

The Senate

Community Affairs
References Committee

Support for Australia's thalidomide
survivors

Interim report

February 2019

© Commonwealth of Australia

ISBN 978-1-76010-904-2 (Printed Version)

ISBN 978-1-76010-904-2 (HTML Version)

This work is licensed under the Creative Commons Attribution-NonCommercial-NoDerivs 3.0 Australia License.



The details of this licence are available on the Creative Commons website:
<http://creativecommons.org/licenses/by-nc-nd/3.0/au/>.

Committee Members

Chair

Senator Rachel Siewert AG, WA

Deputy Chair

Senator Lucy Gichuhi LP, SA
(from 10 September 2018, Deputy Chair from 13 September 2018)

Members

Senator the Hon Kristina Keneally ALP, NSW
Senator Steve Martin Nats, TAS
Senator Louise Pratt ALP, WA
Senator Murray Watt ALP, QLD

Participating Members

Senator Jordon Steele-John AG, WA

Former Members

Senator Slade Brockman LP, WA
(Deputy Chair until 10 September 2018)

Secretariat

Jeanette Radcliffe, Committee Secretary
Kate Gauthier, Principal Research Officer
Michael Kirby, Senior Research Officer
Michael Finch, Research Officer
Marianna Stylianou, Research Officer
Carol Stewart, Administrative Officer

PO Box 6100
Parliament House
Canberra ACT 2600
Phone: 02 6277 3515
Fax: 02 6277 5829
E-mail: community.affairs.sen@aph.gov.au
Internet: www.aph.gov.au/senate_ca

Table of Contents

Committee Members	iii
Terms of Reference	ix
Abbreviations	xi
List of Recommendations	xiii
Chapter 1—Ongoing thalidomide tragedy	1
Introduction	1
Brief history of thalidomide.....	2
Thalidomide in Australia	3
Purpose of the inquiry	5
Scope of the interim report	5
Conduct of the inquiry	5
Submissions.....	6
Hearings.....	7
Acknowledgement	7
Note on references.....	7
Chapter 2—The impact of thalidomide injuries	9
Health impacts.....	10
Congenital malformations.....	12
Thalidomide-induced health conditions	15
Musculoskeletal problems.....	16
Vision and hearing problems.....	17
Issues arising from organ damage	18
Nerve damage	19
Surgery	20
Ageing—early onset of age-related conditions and wear and tear	22
Arthritic conditions	24
Dental deterioration	25
Increasing fatigue and tiredness.....	26
Chronic pain	27

Accidents and injuries	28
Psychosocial and mental health impacts.....	29
Depression.....	30
Bullying and harassment.....	31
Medical practitioners' dismissive and abusive behaviour.....	32
Social wellbeing	33
Committee view	34
Lifelong consequences of thalidomide injuries	35
Difficulty performing everyday tasks.....	35
Lost life opportunities and freedoms.....	37
Impact on parents, family members and carers	37
Trauma and guilt of thalidomide survivors' parents	38
Carer responsibilities	39
Education, workforce participation and forced early retirement	40
Education.....	40
Workforce participation.....	41
Financial wellbeing.....	42
Committee view	44
Chapter 3 – Supports required to live with dignity	45
Health requirements.....	46
Surgeries.....	46
Physiotherapy, massage, chiropractic	47
Cost of physiotherapy, massage and chiropractic services	48
Supports currently available.....	48
Health professionals' understanding of thalidomide injuries.....	49
Lack of knowledge in the medical community about thalidomide	50
Committee view.....	52
Aids to leading an independent life	52
Home modifications	53
Vehicle modifications and mobility aids.....	55
Cost of vehicle modifications.....	55
Disabled parking permits.....	55

National Disability Insurance Scheme	56
Access and support available under the NDIS.....	57
Barriers to access experienced by thalidomide survivors.....	59
Committee view	62
Maintaining survivors' quality of life when greater assistance is required.....	63
Aged care – home care packages	64
Aged care – residential aged care	65
Income supports.....	66
Disability Support Pension.....	66
Income support for family members	68
Committee view	69
Chapter 4 – Compensation and international government responses.....	71
Requests from the Thalidomide Group Australia.....	71
Compensation.....	72
Global context.....	72
Compensation in Australia.....	72
Compensation for thalidomide survivors recognised in the 1970s.....	73
Compensation provided to thalidomide survivors recognised in 2010s.....	76
Unrecognised survivors.....	76
Committee view	78
Government responses to thalidomide in other countries.....	78
Lump sum compensation or one off capitalisation upon recognition	78
Lump sum by assessed level of disability.....	79
Fixed lump sum	80
Ongoing support payments	81
Administered trusts or funds.....	81
Monthly payments	86
Comments from overseas survivors in receipt of assistance	87
Perspective of Australian thalidomide survivors	89
Tax relief and other government programs	91
Apologies	91
Committee view	92

Chapter 5 – Conclusion and recommendations	95
Fifty years of fighting	95
Compensation and the role of the Australian Government.....	96
Coordination and development of further knowledge	97
Making existing supports work more effectively.....	99
National Disability Insurance Scheme.....	99
Medical professions.....	100
Future compensation and the final report.....	100

Terms of Reference

Support for Australia's thalidomide survivors, with particular reference to:

- (a) adequacy of compensation and support;
- (b) responsibility for providing support;
- (c) provision of financial compensation;
- (d) the role of the Australian Government in compensation and support; and
- (e) any related matters.

Abbreviations

ACRRM	Australian College of Rural and Remote Medicine
committee	Senate Community Affairs References Committee
Distillers	Distillers Company Limited
GP	General Practitioner
MBS	Medicare Benefits Schedule
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Act	<i>National Disability Insurance Scheme Act 2013 (Cth)</i>
RACGP	Royal Australian College of General Practitioners

List of Recommendations

Recommendation 1

5.15 The committee recommends that the Department of Health, in consultation with Australia's thalidomide survivors, establish an inter-departmental working group with a view to:

- facilitating easier access to existing Australian Government payments and services; and
- conducting or commissioning additional research about the health and other needs of thalidomide survivors in Australia.

Recommendation 2

5.17 The committee recommends that a contact point for thalidomide survivors should be established in the Department of Health, the Department of Social Services and the National Disability Insurance Agency.

Recommendation 3

5.20 The committee recommends that the Department of Health work with the relevant professional colleges to identify Australian health practitioners who have, or are prepared to acquire, expertise in treating thalidomide injuries.

Recommendation 4

5.22 The committee recommends that if adequate relevant expertise does not exist in Australia, the Department of Health work with professional colleges to ensure appropriate funding assistance is available to enable specialists to learn from international experts who already treat thalidomide survivors.

Recommendation 5

5.24 The committee recommends that the Department of Health conduct a survey of the health of Australia's thalidomide survivors to serve as a baseline assessment for future reference.

Recommendation 6

5.28 The committee recommends that the National Disability Insurance Agency create a guide to assessing and planning appropriate supports for thalidomide survivors.

Recommendation 7

5.31 The committee recommends that the Royal Australian College of General Practitioners, the Royal Australasian College of Physicians and the Australian College of Rural and Remote Medicine take steps to raise awareness of thalidomide and thalidomide injuries, including by incorporating a module on thalidomide injuries in their next round of Continuing Professional Development.

Recommendation 8

5.38 The committee recommends that the Senate extend the date for the presentation of the final report for this inquiry to 22 March 2019.

Chapter 1

Ongoing thalidomide tragedy

...in reality we are still the victims. This categorisation from victim to survivor was in recognition of our parents, especially our mothers, who are the true victims of this disaster, leaving us as the survivors.¹

Introduction

- 1.1 Thalidomide is the common name of the active ingredient in a tablet that was marketed to pregnant women to ease symptoms of morning sickness in the early 1960s.² Though these pregnant mothers had no way of knowing the effects, taking one of these tablets at a crucial stage in the development of the foetus had the capacity to cause the malformation of limbs, facial features and significant internal injuries.
- 1.2 Today, the children of those women are aged in their early-to-mid 50s and as noted above they identify as survivors.
- 1.3 Throughout this inquiry, the Senate Community Affairs References Committee (committee) has received compelling personal accounts from thalidomide survivors and their families. Survivors told the committee about the ways their lives have been profoundly impacted and, in many aspects, diminished by the severe injuries caused to their bodies by thalidomide. These injuries have affected survivors throughout their entire lives, and includes: complex and chronic health conditions; significant disabilities requiring specialised supports; mental illness; poor social and emotional wellbeing; chronic pain; reduced life opportunities; and significant personal financial costs.
- 1.4 Despite these effects, thalidomide survivors are still fighting to retain their independence, their dignity and to have their voices heard. Thalidomide survivors urged the committee to support their request for compensation, support and an apology for their families.
- 1.5 The families of thalidomide survivors, particularly survivors' parents, spouses and children, live with the effects of what thalidomide did to the person they love. Evidence before the committee conveys the trauma, guilt, and life changing carer responsibilities experienced by survivors' parents. The spouses and children of survivors have missed life opportunities and continue to make considerable personal commitments as they provide care and support to their loved one.

¹ Mr Lance Fletcher, Founder and President, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 40.

² The full name of the drug was alpha-phthalimido-glutarimide.

Brief history of thalidomide

- 1.6 Thalidomide was initially produced and released by Chemie Grünenthal in 1957 as a very safe sedative.³ Unlike other sedatives on the market, an overdose of thalidomide was thought to result in a deep sleep with no other side effects, whereas some other sedatives were lethal on overdose.⁴ The drug was marketed as safe and 'non-toxic', including statements that researchers 'could not find a dose high enough to kill a rat'.⁵ It was considered to be a 'wonder drug'.⁶
- 1.7 On the basis that it was safe, the drug was marketed as being effective for treating insomnia, headaches, as well nausea and morning sickness during pregnancy.⁷
- 1.8 Between the late 1950s and early 1960s, thalidomide was distributed in 46 countries and provided to thousands of pregnant women.⁸ In the years after its release, thalidomide was linked to nerve damage.⁹ Obstetricians also started to notice an increase in the number of severe birth defects, especially upper limb malformations.¹⁰
- 1.9 In late 1961, two doctors Dr Widukind Lenz in Germany and Dr William McBride, an obstetrician from Sydney, independently reached the conclusion that thalidomide was responsible for the birth malformations.¹¹ Dr Lenz raised his concerns directly with the manufacturer, Chemie Grünenthal. The medical community in Australia was alerted at a similar time to the link between birth

³ Neil Vargesson, 'Thalidomide embryopathy: an enigmatic challenge', *Development Biology*, 2013, p. 1.

⁴ Sahar Mansour, Emma Baple and Christine M Hall, 'A clinical review and introduction of the diagnostic algorithm for thalidomide embryopathy', *Journal of European Hand Surgery*, 2018, p. 1.

⁵ Thalidomide Group Australia, *Submission 1*, p. 7.

⁶ UK Thalidomiders Campaign Team, *Submission 4*, p. 1; Neil Vargesson, 'Thalidomide embryopathy: an enigmatic challenge', *Development Biology*, 2013, p. 1.

⁷ Department of Health, *Submission 2*, p. 1.

⁸ Elizabeth Newbronner and Karl Atkin, 'The changing health of Thalidomide survivors as they age: A scoping review', *Disability and Health Journal*, 2018, [p. 184].

⁹ Neil Vargesson, 'The teratogenic effects of thalidomide on limbs', *Journal of European Hand Surgery*, 2018, p. 1; Neil Vargesson, 'Thalidomide-induced teratogenesis: history and mechanisms', *Birth Defects Research (Part C)*, 2015, p. 140.

¹⁰ Neil Vargesson, 'Thalidomide-induced teratogenesis: history and mechanisms', *Birth Defects Research (Part C)*, 2015, p. 140.

¹¹ Debra Kennedy, 'Thalidomide: a byword for tragedy', *O&G Magazine*, vol. 18, no. 1, 2016, <https://www.ogmagazine.org.au/18/1-18/thalidomide-byword-tragedy/> (accessed 13 November 2018); Neil Vargesson, 'Thalidomide-induced teratogenesis: history and mechanisms', *Birth Defects Research (Part C)*, 2015, p. 140.

malformations and thalidomide when Dr McBride wrote a letter in the medical journal *The Lancet*.¹²

- 1.10 The drug was withdrawn from sale by the manufacturer and the international distributors shortly thereafter.¹³
- 1.11 It is estimated that that approximately 40 per cent of children born with thalidomide-induced defects died in in their first year of life and over 10 000 children were born with severe congenital defects as a result of thalidomide.¹⁴

Thalidomide in Australia

- 1.12 In Australia, products containing thalidomide were distributed and sold by the Australian arm of a British alcoholic beverage firm, Distillers Co. According to Department of External Affairs' cables from the time, products containing thalidomide were sold in Australia by Distillers Co. (Biochemicals) Aust. Pty Ltd between 1 August 1960 and 29 November 1961.¹⁵
- 1.13 Products containing thalidomide were sold under a number of names for different clinical indications: Distaval (sedative and hypnotic), Valgraine (for treating miagraines), Asmaval (for asthma), Valgis (for headaches) and Tensival (for pre-menstrual tension).¹⁶
- 1.14 In all states except Queensland, these drugs were at some time available without a prescription.¹⁷ In some cases, sales representatives visited doctors' clinics and provide free samples of the drug, which were in turn passed on to patients.¹⁸ Some of those patients were the mothers of today's survivors.
- 1.15 As a result of pregnant women taking only one or two tablets, thalidomide survivors were born with significant malformations of limbs, eyes, ears as well as less visible internal malformations including significant organ and nerve damage.¹⁹

¹² WG McBride, 'Thalidomide and congenital abnormalities', *The Lancet*, vol. 278, 16 December 1961, p. 1358. See also, Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 22.

¹³ Thalidomide Group Australia, *Submission 1 – Attachment 1*, pp. 21–22.

¹⁴ Thalidomide Group Australia, *Submission 1*, p. 7; Department of Health, *Submission 2*, [p. 1].

¹⁵ Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 21. See also *The Distillers Company (Bio-chemicals) Limited (Appeal No. 12 of 1969) v Laura Ann Thompson by Arthur Leslie Thompson her next Friend & The Distillers Company Bio-chemicals (Australia) Pty. Limited* [1971] UKPC 3, p. 2.

¹⁶ Thalidomide Group Australia, *Submission 1 – Attachment 1*, pp. 2, 13.

¹⁷ Whether thalidomide required a prescription varied over time and by state. See, for example: Thalidomide Group Australia, *Submission 1*, p. 7; Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 13.

¹⁸ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 115.

¹⁹ Neil Vargesson, 'Thalidomide embryopathy: an enigmatic challenge', *Development Biology*, 2013, p. 1.

- 1.16 In the early 1970s, the parents of a small group of thalidomide survivors tried to obtain compensation from Distillers Company Limited (Distillers).²⁰ Distillers eventually settled the case and recognised 40 Australian and New Zealand survivors.²¹ This group became the originally recognised group of Australian thalidomide survivors. Of this group, there are currently 36 Australian thalidomide survivors.
- 1.17 As part of the settlement, a modest amount of money was placed in trust for each thalidomide survivor according to the nature of their disability and in exchange survivors' parents were required to sign a waiver against further legal action against Distillers or Grünenthal and a confidentiality agreement. Further details about the settlement are noted in Chapter 4 of this report.
- 1.18 This modest settlement would represent the only compensation that thalidomide survivors would receive for the next 50 years.
- 1.19 In 1997, Distillers was purchased by British drinks manufacturer Diageo. As part of that purchase, Diageo inherited the legal liabilities of Distillers Co., including the thalidomide legacy.²²
- 1.20 In the 2000s, English thalidomide survivors had approached Diageo and secured a further provision to assist thalidomide survivors in the United Kingdom.²³ In 2010, the father of one of the recognised Australian thalidomide survivors led an effort to obtain additional compensation from Diageo for Australia's thalidomide survivors. Diageo, after some negotiation, agreed to provide ex gratia payments to the recognised thalidomide survivors for at least 18 years. Those payments will expire in approximately 2028. Further details about the ex gratia payments can be found in Chapter 4 of this report.
- 1.21 At about a similar time, a group of newly identified previously uncompensated thalidomide survivors inquired about whether they were eligible for the ex gratia scheme. When Diageo declined to include them in the ex gratia scheme, a class action was commenced in Victoria.²⁴ By the time the

²⁰ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 290. See also *The Distillers Company (Bio-chemicals) Limited (Appeal No. 12 of 1969) v Laura Ann Thompson by Arthur Leslie Thompson her next Friend & The Distillers Company Bio-chemicals (Australia) Pty. Limited* [1971] UKPC 3.

²¹ Mrs Lesley Fletcher, Founder and Former Secretary, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

²² Ms Lisa McManus, Director, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 4; Mr Peter Gordon, Senior Partner, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 28.

²³ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 28.

²⁴ Mr Peter Gordon, *Submission 66*, [p. 4].

class action was completed, the class consisted of 107 members and was settled by Diageo for approximately \$89 million.²⁵

Purpose of the inquiry

1.22 This inquiry considers what effect thalidomide malformations and injuries have had on the lives of survivors and their families, whether the supports that are currently available to survivors are sufficient to support them appropriately as they age and whether the compensation that they have received to date has been adequate.

Scope of the interim report

1.23 This interim report focuses on the experiences of thalidomide survivors and their families in dealing with the severe challenges that thalidomide has presented. This report considers how thalidomide has affected survivors' lives and the lives of their immediate families, what supports are available and what supports they might need and whether they have the appropriate resources to live an independent and dignified life as they age.

1.24 In its final report, the committee will focus on the companies and institutions that existed at the time that thalidomide was distributed in Australia and whose actions allowed at least 100 Australians to develop serious debilitating disabilities. The committee's final report will include a more detailed examination of the role of the Australian Government, both at the time thalidomide was available for sale in Australia and its role in supporting thalidomide survivors in subsequent years. The final report will make final recommendations about the way Australia's thalidomide survivors should be supported going forward.

1.25 Following this introductory chapter, this report consists of four chapters:

- **Chapter 2** considers the impacts thalidomide has had on survivors and their families;
- **Chapter 3** considers the support requirements of thalidomide survivors and whether existing supports are adequate to meet survivors' needs;
- **Chapter 4** considers what compensation has been provided to thalidomide survivors and whether this is sufficient in light of international schemes; and
- **Chapter 5** provides the committee's conclusions and recommendations.

Conduct of the inquiry

1.26 On 21 August 2018 the Senate referred the Support of Australia's thalidomide survivors to the committee for inquiry and report by 28 November 2018 with the following terms of reference:²⁶

²⁵ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 310.

- (a) adequacy of compensation and support;
- (b) responsibility for providing support;
- (c) provision of financial compensation;
- (d) the role of the Australian Government in compensation and support; and
- (e) any related matters.²⁷

- 1.27 On that day, the Senate granted the committee an extension of time to report to the last sitting Wednesday of February 2019.²⁸ The committee sought this reporting extension to facilitate additional time to hold a second public hearing for the inquiry.
- 1.28 After receiving crucial evidence at the public hearing in Sydney on 31 January 2019, the committee requested a further extension to enable it time to complete its final report.

Submissions

- 1.29 In accordance with its usual practice, the committee advertised the submission on its website and issued 38 invitations to organisations the committee considered may have had relevant knowledge that may have assisted the committee. The committee requested that submissions be lodged by 21 September 2018. The committee continued to accept submissions after this date. The committee also issued two press releases to advertise the inquiry.
- 1.30 The committee received 68 submissions to the inquiry. Submissions were made primarily by thalidomide survivors and their families; submissions were also made by several organisations and other individuals with knowledge relevant to the inquiry.
- 1.31 The submissions received by the committee are published on the committee's inquiry webpage.²⁹
- 1.32 To protect the privacy of individuals who were often providing detailed personal information in the context of a public inquiry, the committee agreed to receive submissions from individuals submitting in personal capacity as name withheld.

²⁶ *Journals of the Senate*, No. 111, 21 August 2018, pp. 3555–3556.

²⁷ See: Community Affairs References Committee, *Support for Australia's thalidomide survivors*, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ThalidomideSurvivors (accessed 11 February 2019).

²⁸ *Journals of the Senate*, No. 132, 28 November 2018.

²⁹ See: Community Affairs References Committee, *Support for Australia's thalidomide survivors—Submissions*, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ThalidomideSurvivors/Submissions (accessed 11 February 2019).

Hearings

- 1.33 The committee held two public hearings for its inquiry. The first hearing was held in Melbourne on 2 November 2018, and the second hearing in Sydney on 31 January 2019. The committee heard from thalidomide survivors and other witnesses relevant to the inquiry at these hearings.
- 1.34 Transcripts of the hearings are available on the committee's inquiry webpage. A list of witnesses who provided evidence at each hearing is also available.³⁰
- 1.35 During this inquiry, the committee agreed to ask witnesses appearing providing lived experience evidence to use their first name only. The committee places a high value on this evidence and used the practice to ensure that the privacy of individuals who volunteer to provide detailed personal information to the committee is protected as much as possible.

Acknowledgement

- 1.36 The committee extends its thanks to all those who contributed to the inquiry.
- 1.37 In particular, the committee would like to recognise and thank the thalidomide survivors and their families who participated in the inquiry. The committee recognises that the evidence provided by survivors and their families was deeply personal and often painful to share. Personal account evidence is central to this report and the committee thanks survivors and their families for sharing their experiences.

Note on references

- 1.38 In this report, references to *Committee Hansard* are to proof transcripts. Page numbers may vary between proof and official transcripts.

³⁰ See: Community Affairs References Committee, *Support for Australia's thalidomide survivors—Public hearings*, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ThalidomideSurvivors/Public_Hearings (accessed 11 February 2019).

Chapter 2

The impact of thalidomide injuries

That one little pill destroyed my body inside and out. Thalidomide is like tossing a stone into the water: it causes a ripple effect. The drug didn't just destroy me; it rippled onto my parents, my siblings, my family, my ambitions, my relationships, my jobs, my earnings, my health—my everything.¹

- 2.1 Thalidomide survivors and their families have been, and continue to be, profoundly impacted by the often catastrophic injuries caused by thalidomide. The evidence provided to the committee makes clear that for many thalidomide survivors, every aspect of their lives is either made more difficult, or is diminished, by the acute damage thalidomide has caused to their bodies.
- 2.2 Thalidomide survivors were born with a range of malformations due to the teratogenic effects of thalidomide.² Often, these malformations were severe and extensive. The congenital malformations afflicting survivors can be visible, such as malformed limbs, or invisible, such as damage to internal organs and nerve systems. Congenital malformations have caused thalidomide survivors to suffer from a lifetime of functional impairment. As a further result of thalidomide-induced injuries and impairments, thalidomide survivors suffer from chronic health conditions, psychosocial impacts, increasing 'wear and tear' on their bodies, age-related conditions beyond their years, and newly recognised or late onset symptoms.
- 2.3 Despite immense challenges, survivors fight daily to overcome their thalidomide injuries, to contribute to society, and to live their lives in a regular and dignified way. This, in part, is achieved by thalidomide survivors adapting their bodies to perform ordinary tasks in unusual ways, such using their feet and mouths in lieu of functional upper limbs. Evidence provided to the committee suggests that as thalidomide survivors age, such necessary adaptations are becoming increasingly unsustainable. Survivors report they are currently experiencing wear and tear on their bodies, in addition to already complex and deteriorating health conditions. As thalidomide survivors' health continues to be effected, there are associated impacts on their functionality and independence.
- 2.4 Thalidomide survivors and their families have been systemically disadvantaged in living their day-to-day lives. Thalidomide injuries have meant that survivors are disadvantaged in accessing education and employment, face the significant financial burdens associated with

¹ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

² Note, a teratogen is an agent which can adversely impact the development of an embryo.

thalidomide injuries and poor health, and have been socially ostracised in many instances.

- 2.5 This chapter considers the impact of thalidomide injuries on Australia's thalidomide survivors and their families. The committee particularly considered the complex and developing health impacts reported by thalidomide survivors, and the consequential disadvantages they have faced. The thalidomide injuries content of this chapter precludes the content of Chapter 3, which considers what supports are required by survivors to effectively manage the impacts of their thalidomide injuries.

Health impacts

- 2.6 Thalidomide was marketed as a safe drug to use.³ Despite this, thalidomide can cause significant damage to vertebrate embryos during sensitive periods of development.⁴ The congenital malformations caused by thalidomide are collectively referred to as thalidomide embryopathy.⁵ The committee was told that thalidomide has an array of different actions, and given this, 'thalidomide causes an incredible amount of damage in embryos, which varies in severity between individuals.'⁶
- 2.7 The impact of thalidomide on an embryo is time dependent, rather than dose dependent, and as such even a single dose of thalidomide at a particular time can have significant impact.⁷ This is known as the time sensitive window, which is understood to extend 20–36 days after fertilisation.⁸ Thalidomide may also have the ability to damage embryos in the late stage of development and there may be 'no time in pregnancy that is safe from the effects of thalidomide.'⁹ Unbeknownst to the mother consuming thalidomide, the time at which thalidomide was taken influenced the type of congenital malformations

³ Thalidomide Group Australia, *Submission 1*, p. 1; UK Thalidomiders Campaign Team, *Submission 4*, [p. 1]; Thalidomide Victims Association of Canada, *Submission 59 – Attachment 1*, p. 1.

⁴ Professor Neil Vargesson, *Submission 62*, [p. 1].

⁵ Elizabeth Newbronner and Karl Atkin, 'The changing health of Thalidomide survivors as they age: A scoping review', *Disability and Health Journal*, vol. 11, issue 2, 2018, p. 184.

⁶ Professor Neil Vargesson, Information provided following appearing at the committee's public hearing on 31 January 2019, additional information, [p. 1] (received 6 February 2019).

⁷ Alessia Nicotra, Claus Newman, Martin Johnson, Oleg Eremin, Tim Friede, Omar Malik, Richard Nicholas, 'Peripheral Nerve Dysfunction in Middle-Aged Subjects Born with Thalidomide Embryopathy', *PLoS ONE*, vol. 11, issue 4, 2016, p. 2.

⁸ Neil Vargesson, 'Thalidomide Induced Teratogenesis: History and Mechanisms', *Birth Defects Research (Part C)*, vol. 105, 2015, p. 144.

⁹ Professor Neil Vargesson, Information provided following appearing at the committee's public hearing on 31 January 2019, additional information, [p. 1] (received 6 February 2019).

their child would be born with. For example, phocomelia of arms occurs between 24–33 gestational days.¹⁰

- 2.8 The congenital malformations associated with thalidomide embryopathy are wide ranging, and have had shocking consequences for thalidomide survivors. The wide ranging malformations of thalidomide embryopathy mean that '...no two thalidomide survivors are the same.'¹¹ This variation in thalidomide survivors congenital malformations has resulted in varying complex health conditions for survivors.
- 2.9 Thalidomide survivors' health conditions that are attributable to thalidomide embryopathy, but which go beyond survivors' congenital malformations, are often referred to as consequential impacts. Thalidomide survivors are experiencing a range of consequential impacts, including evolving health outcomes such as early-onset of age related conditions, wear and tear on their bodies, and late onset symptoms.
- 2.10 Ms Elizabeth Newbronner, an academic with a background in researching the impacts of thalidomide on survivors, suggested there are three 'root causes' of thalidomide survivors' thalidomide-related physical health conditions:
- (1) **Thalidomide damage**—including the deterioration of the damage known to be caused by thalidomide, the emergence of new damage, and improved understanding of known thalidomide damage;
 - (2) **Accidents and injuries**—occurring as a result of existing thalidomide impairments; and
 - (3) **Premature 'wear and tear'**—arising from survivors' adaption of their bodies to compensate for their original thalidomide damage.¹²
- 2.11 As thalidomide survivors age, the consequential health impacts of thalidomide are worsening with adverse impacts for thalidomide survivors' levels of impairment and, for survivors with more severe damage, further limitations on their already restricted independence.¹³ Living with physical impairments and chronic health conditions that restrict thalidomide survivors' independence has had psychosocial impacts both on survivors and their families.¹⁴ Submissions to the inquiry have described psychosocial impacts as including: depression; suicidal ideations; anxiety; and social isolation. The

¹⁰ Janet McCredie, *Beyond Thalidomide: Birth Defects Explained*, Royal Society of Medicine Press Ltd, London, p. 17.

¹¹ Professor Neil Vargesson, *Committee Hansard*, 31 January 2019, p. 4.

¹² Ms Elizabeth Newbronner, *Submission 63*, p. 2.

¹³ Ms Elizabeth Newbronner, *Submission 63*, p. 2.

¹⁴ UK Thalidomiders Campaigns Team, *Submission 4*, [p. 2].

adverse psychosocial impacts experienced by Australia's thalidomide survivors are consistent with submissions describing the psychosocial and mental health impacts of thalidomide on survivors in the United Kingdom and Germany.¹⁵

- 2.12 This section of the report considers the evidence received from thalidomide survivors and their families on the impacts thalidomide has on survivors' health. In particular, the committee considered evidence which indicates that, in addition to the already significant health impacts faced by thalidomide survivors, their health outcomes are becoming increasingly complex, and are worsening, as survivors age.

Congenital malformations

- 2.13 The congenital malformations caused by thalidomide were often lethal. Submissions received from Thalidomide Group Australia and the Department of Health estimate that 40 per cent of the babies affected by thalidomide died during their first year of life.¹⁶ Another estimate provided to the committee went further and suggested that of the approximately 10 000 babies born globally with thalidomide embryopathy, just half survived.¹⁷ Ken, a thalidomide survivor, told the committee that his twin brother was still born as a result of thalidomide.¹⁸
- 2.14 Australia's thalidomide survivors live with an array of thalidomide-induced congenital malformations associated with thalidomide embryopathy. These malformations were summarised during the inquiry as follows: eye and face muscle defects; absence of auricles and deafness; absent of hypoplasia of arms; absent fingers and thumbs with three joints; defects of the femur and tibia; malformations of the heart, bowel, uterus, digestive track and gallbladder; and defects of the spine.¹⁹
- 2.15 The most common congenital malformation afflicting thalidomide survivors is malformed limbs, a condition known as phocomelia.²⁰ Research on thalidomide-induced limb malformations has previously suggested that limb defects are the most common malformations found in thalidomide-affected people because 'internal organ defects induced through effects on

¹⁵ See, for example, UK Thalidomiders Campaigns Team, *Submission 4*, [p. 2]; Ms Elizabeth Newbronner, *Submission 63*, pp. 2–3; The Thalidomide Society, *Submission 61—Attachment 1*, p. 6; Thalidomide Victims Association of Canada, *Submission 59—Attachment 2*, p. 54.

¹⁶ Thalidomide Group Australia, *Submission 1*, p. 4; Department of Health, *Submission 2*, [p. 1].

¹⁷ Thalidomide Victims Association of Canada, *Submission 59—Attachment 1*, p. 1.

¹⁸ Ken, *Committee Hansard*, 31 January 2019, p. 49.

¹⁹ Thalidomide Group Australia, *Submission 1*, p. 7; Department of Health, *Submission 2*, [p. 1].

²⁰ Elizabeth Newbronner and Karl Atkin, 'The changing health of Thalidomide survivors as they age: A scoping review', *Disability and Health Journal*, vol. 11, issue 2, 2018, p. 184.

vascularisation, as the organ was forming, were likely lethal in utero.²¹ The UK Thalidomiders Campaigns Team described the limb malformations associated with thalidomide embryopathy in its submission:

The main impairments caused by Thalidomide affect the limbs and are usually bilateral, both arms, both legs, or all four limbs. The most severe impairment is known as phocomelia, a condition where the long bones of some or all limbs are misshapen and where the hands and feet, which can be either, malformed or rudimentary, arise from the trunk. Impairments cover a wide spectrum of limb disabilities ranging from a substantial shortening of the limbs or entire limblessness, to fused fingers. One of the trademark features of Thalidomide is missing thumbs.²²

2.16 Personal account evidence submitted to the inquiry outlines the diverse range of congenital malformations affecting thalidomide survivors. The congenital malformations reported to the committee include:

- malformed or absent limbs, including phocomelia;²³
- malformed hands, including absent fingers or thumbs;²⁴
- internal organ malformations;²⁵
- malformed ears or absent ear components and associated hearing loss;²⁶
- paralysis of facial muscles and facial malformations;²⁷
- spinal malformations, including scoliosis;²⁸
- damaged or absent nerves, including cranial and peripheral nerve damage, and facial palsy and Moebius syndrome;²⁹

²¹ Neil Vargesson, 'Thalidomide-induced limb defects: resolving a 50-year-old puzzle', *BioEssays*, vol. 31, issue 12, 2009, p. 1331.

²² UK Thalidomiders Campaigns Team, *Submission 4*, [p. 1].

²³ See, for example, Rick, *Committee Hansard*, 2 November 2018, p. 15; Mary, *Committee Hansard*, 2 November 2018, p. 16; Mandy, *Committee Hansard*, 2 November 2018, p. 18; Name withheld, *Submission 8*, [p. 1]; Name withheld, *Submission 9*, [p. 1]; Name withheld, *Submission 14*, p. 1; Name withheld, *Submission 11*, p. 1; Name withheld, *Submission 15*, [p. 1]; Name withheld, *Submission 17*, [p. 1]; Name withheld, *Submission 18*, [p. 1]; Name withheld, *Submission 29*, [p. 1]; Name withheld, *Submission 30*, [p. 1]; Name withheld, *Submission 32*, [p. 1]; Name withheld, *Submission 41*, [p. 1]; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 48*, [p. 1].

²⁴ See, for example, Name withheld, *Submission 9*, [p. 1]; Name withheld, *Submission 14*, p. 1; Name withheld, *Submission 17*, [p. 1]; Name withheld, *Submission 18*, [p. 1]; Name withheld, *Submission 27*, p. 1; Name withheld, *Submission 28*, p. 1; Name withheld, *Submission 35*, [p. 1]; Name withheld, *Submission 38*, [p. 1].

²⁵ See, for example, Name withheld, *Submission 14*, p. 1; Name withheld, *Submission 29*, [p. 1]; Name withheld, *Submission 60*, [p. 1].

²⁶ See, for example, Name withheld, *Submission 9*, p. [1]; Name withheld, *Submission 25*, p. 2; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 57*, [p. 1].

²⁷ See, for example, Name withheld, *Submission 25*, p. 2; Name withheld, *Submission 27*, [p. 1]; Name withheld, *Submission 35*, [p. 1].

²⁸ See, for example, Name withheld, *Submission 27*, p. [1]; Name withheld, *Submission 41*, [p. 1].

- deformed anus;³⁰
- other additional and absent body components;³¹ and
- eye disorders resulting in vision impairments, including Duane syndrome.³²

2.17 At the time thalidomide survivors were born in Australia, medical knowledge may have been insufficient to identify their congenital malformations as being caused by thalidomide. The mother of a thalidomide survivor told the committee:

The obstetrician too was shocked and had no explanation for how my baby should be so different. There were no similar birth defects known to any of the doctors, pediatricians or [ear, nose and throat] specialists. For the first few years there was no definite explanation but gradually the belief that Thalidomide was the culprit began to emerge. I recalled having taken Thalidomide Distaval as a sedative on one occasion early in my pregnancy and found the rest of the sample pack on my return home from hospital.³³

2.18 For that mother, it was not until her son was seen by a paediatric ear, nose and throat specialist in the United Kingdom that thalidomide embryopathy was recognised.³⁴ Identification of the symptoms of thalidomide embryopathy can be a challenge in the present day, particularly if it is unclear as to whether an effected person's mother took thalidomide, noting that there are other congenital conditions that present thalidomide-like malformations.³⁵ In providing evidence at the committee's public hearing in Sydney, Mr Peter Gordon, Senior Partner at Gordon Legal, said:

...there is a horrendous but also very wide range of injuries that thalidomide causes. There may be people in this room or sitting around this table who may have thalidomide disabilities. We simply don't know what they are, because the breadth of the spectrum of thalidomide injuries has never been properly mapped. We still don't understand with certainty what the biological mechanisms are—we know that there are more than one—that cause those injuries.³⁶

²⁹ See, for example, Name withheld, *Submission 28*, [p. 1]; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 57*, [p. 1].

³⁰ See, for example, Name withheld, *Submission 57*, [p. 1].

³¹ See, for example, Name withheld, *Submission 18*, [p. 1]; Name withheld, *Submission 27*, [p. 1]; Name withheld, *Submission 32*, [p. 1]; Name withheld, *Submission 11*, p. 1.

³² See, for example, Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 57*, [p. 1].

³³ Name withheld, *Submission 25*, p. 2.

³⁴ Name withheld, *Submission 25*, p. 3.

³⁵ Neil Vargesson, 'Thalidomide-induced teratogenesis: history and mechanisms', *Birth Defects Research (Part C)*, vol. 105, 2015, p. 145.

³⁶ Mr Peter Gordon, Senior Partner, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 29.

- 2.19 In providing evidence to the committee, Professor Janet McCredie and Professor Neil Vargesson agreed that it is possible there are people with less visible forms of thalidomide damage for which existing processes have not identified as being affected by thalidomide.³⁷
- 2.20 The committee notes that some of Australia's thalidomide survivors' health conditions were last formally assessed in 2010, as part of the process by which the Australian distributor of thalidomide agreed to provide financial support to identified thalidomide survivors.³⁸ There has not been a formal reassessment of those survivors' health conditions, nor does there appear to be plans to do so.³⁹ The committee received evidence from at least one survivor indicating their health has deteriorated since that previous health assessment in 2010.⁴⁰ Other evidence before the committee suggests that the deterioration of thalidomide survivors' health may not have been fully accounted for in that previous health assessment.⁴¹

Thalidomide-induced health conditions

- 2.21 Thalidomide survivors experience a range of consequential health conditions beyond their initial congenital malformations.⁴² Thalidomide survivors experience higher than average prevalence of musculoskeletal problems, pain, dental problems, deteriorating sight and hearing, and mental health conditions.⁴³ The committee received some evidence indicating that thalidomide survivors have died prematurely as a result of complications of thalidomide injuries.⁴⁴
- 2.22 For some survivors, the consequential health impacts of thalidomide began very early in life. The committee heard evidence that one thalidomide survivor, at approximately seven weeks of age, was diagnosed with a thalidomide-induced condition that affected the ability of their body to

³⁷ Professor Janette McCredie, *Committee Hansard*, 31 January 2019, p. 7; Professor Vargesson, *Committee Hansard*, 31 January 2019, p. 7.

³⁸ Mrs Lesley Fletcher, Former Secretary and Founder, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

³⁹ Mr Tim Kelly, Trustee, Thalidomide Australia Fixed Trust, *Committee Hansard*, 31 January 2019, pp. 10–11.

⁴⁰ Vicki, *Committee Hansard*, 31 January 2019, p. 17.

⁴¹ Mark, *Committee Hansard*, 31 January 2019, p. 25.

⁴² Ms Elizabeth Newbronner, *Submission 63*, p. 1.

⁴³ Elizabeth Newbronner and Karl Atkin, 'The changing health of thalidomide survivors as they age: a scoping review', *Disability and Health Journal*, vol. 11, 2018, pp. 187–189.

⁴⁴ Ms Lisa McManus, Director, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 1; Mary, *Committee Hansard*, 2 November 2018, p. 16; Mr Peter Gordon, Senior Partner, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 28.

adequately hydrate and provide nutrition. This condition, coupled with other gut malformations, impacted on the development of their brain and ability to learn.⁴⁵

- 2.23 On top of thalidomide survivors' extensive health issues, some survivors are now experiencing late onset, or newly emergent, health conditions related to thalidomide. The UK Thalidomiders Campaign Team submitted that most thalidomide survivors report experiencing at least four of five severe late-onset health issues.⁴⁶

Musculoskeletal problems

- 2.24 Some thalidomide survivors advised the committee that they had developed musculoskeletal problems because of their thalidomide injuries. Mark, a thalidomide survivor, explained that his most debilitating disability was his back pain:

My arms are my deformity; my chronic back pain is my disability.⁴⁷

- 2.25 A survivor suggested to the committee that the scoliosis he has may be the result of thalidomide. This survivor has to have four major back surgeries to manage his severe spinal scoliosis which has left him with a chronic pain condition that severely impedes his quality of life.⁴⁸ For that survivor, any bending activity, including doing domestic activities such as packing a dishwasher, exacerbate his scoliosis.⁴⁹
- 2.26 A number of other thalidomide survivors told the committee that they also suffered some form of scoliosis.⁵⁰ One survivor's experience of spinal curvature lead to significant consequential impacts, including multiple surgeries:

By ten years of age [the survivor's] spine began to curve and quite quickly he had a curvature of 56* which made his left chest press on his heart. Then started the years of repeated surgical operations which tried to straighten the spine. He lived in vests to hold him in place, Each operation fused more and more of his vertebrae until he finally had all the vertebrae fused (bone harvested from hips etc) and it was finished off with a steel plate in the sacrum area.⁵¹

⁴⁵ Confidential, *Submission 7*.

⁴⁶ UK Thalidomiders Campaign Team, *Submission 4*, [p. 1].

⁴⁷ Mark, *Committee Hansard*, 31 January 2019, p. 20.

⁴⁸ Name withheld, *Submission 50*, [p. 1].

⁴⁹ Name withheld, *Submission 50*, [p. 2].

⁵⁰ See, for example, Joanne, *Committee Hansard*, 31 January 2019, p. 23; Fiona, *Committee Hansard*, 31 January 2019, p. 24; Lou, *Committee Hansard*, 31 January 2019, p. 49; Name withheld, *Submission 41*, p. 1.

⁵¹ Name withheld, *Submission 51*, [p. 1].

2.27 Ken, a thalidomide survivor, described experiencing pain in his back commensurate with a slipped disc which was not attributable to thalidomide embryopathy, however this pain is aggravated by the way he has to move his body to compensate for the effects of thalidomide-induced congenital arm malformations.⁵² Ken also explained the impact the fusion of his radial long bones in his elbows has on his functionality:

...I cannot rotate my wrists, making everyday tasks difficult to perform. For example, collecting change at a shop involves me dropping my shoulder and twisting my spine to pick up my hands to receive the coins. I also find it difficult to open jars and bottles and to pick up things like paper. It has also meant that my arms are bent and I am unable to extend them.⁵³

2.28 Restricted or no wrist rotation is also experienced by other thalidomide survivors.⁵⁴

Vision and hearing problems

2.29 Thalidomide survivors with congenital malformations to their eyes and ears have faced vision and hearing problems throughout their lives. As thalidomide survivors age, survivors are experiencing the consequential impacts of deteriorating vision and hearing.⁵⁵ Vicki, a thalidomide survivor, expressed her fear regarding the uncertainty of potentially losing her hearing and sight as a result of thalidomide injuries:

The thing that frightens me is that I've got the chance of going deaf and blind. I didn't realise the thalidomide is rapidly compounding the effect on my sight and my hearing. I don't know what I'm going to do about that. I've had operations. I'm waiting on an operation on my left ear to see if they can open up the canal any more, but no-one will touch me. I did find one guy who said he'd have a go, so that's all right. Anyway, like most of us, we're just after some answers on what's going to happen.⁵⁶

2.30 The committee heard how vision impairments impact thalidomide survivors' lives and interfere with their ability to work;⁵⁷ their ability to lip read (for a survivor who is also deaf);⁵⁸ and engage in recreational activity.⁵⁹ Some

⁵² Ken, *Committee Hansard*, 31 January 2019, pp. 49–50.

⁵³ Ken, *Committee Hansard*, 31 January 2019, p. 50.

⁵⁴ Name withheld, *Submission 9*, [p. 1]; Name withheld, *Submission 39*, [p. 1]; Name withheld, *Submission 43*, [p. 1].

⁵⁵ Name withheld, *Submission 35*, p. 1.

⁵⁶ Vicki, *Committee Hansard*, 31 January 2019, p. 16.

⁵⁷ Andrew, *Committee Hansard*, 31 January 2019, p. 17; Vicki, *Committee Hansard*, 31 January 2019, pp. 16–17.

⁵⁸ Name withheld, *Submission 25*, p. 25.

⁵⁹ Name withheld, *Submission 36*, [p. 1].

thalidomide survivors are experiencing deterioration in their eyesight condition.⁶⁰ One survivor told the committee that the deterioration of their sight is accelerating:

...my eyesight is failing more dramatically. With glasses and surgery I have been fortunate but my eyesight is getting worse and again the longer term prognosis is the same – little or none in the end. I understand that these senses deteriorate in older people anyway but as a Thalidomider everything is sped up as we age so losing these important senses I believe will occur much sooner than normal.⁶¹

2.31 Ms Elizabeth Newbronner noted in her submission that results from a 2015 health and wellbeing survey of United Kingdom thalidomide survivors shows that 'nearly half the survey respondents said they had deteriorating sight/eye problems' and 'a third had deteriorating hearing/other ear problems'.⁶²

2.32 Whilst glasses or contact lenses can assist in vision correction, thalidomide survivors with no ears or functional arms will have trouble using these supports:

Problems with sight and hearing are common as people get older, and Thalidomiders are no different, with two-fifths of UK Thalidomiders reporting worsening sight. However the problem with Thalidomiders is how to correct their sight when they have no ears to hold their glasses on and no arms or hands to put in contact lenses.⁶³

2.33 As someone with no ears or arms may not be able to wear glasses or contact lenses the importance of thalidomide survivors access to eye surgery has been highlighted to the committee.⁶⁴ However the cost of surgery to correct eye conditions can be prohibitive for thalidomide survivors:

When I eat my eye involuntarily weeps and it doesn't blink. The operations to fix my eye would be very expensive so I endure alternating dryness, constant irritation and weeping, it's there all the time. ⁶⁵

Issues arising from organ damage

2.34 Internal organ malformations are one of the invisible damages caused by thalidomide. Thalidomide survivors' congenital malformations to internal organs normally affect their kidneys, lungs, intestinal tract and heart.⁶⁶

⁶⁰ Name withheld, *Submission 43*, [p. 1].

⁶¹ Name withheld, *Submission 36*, [p. 2].

⁶² Ms Elizabeth Newbronner, *Submission 63*, pp. 1–2.

⁶³ UK Thalidomiders Campaign Team, *Submission 4*, [p. 2].

⁶⁴ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 9.

⁶⁵ Name withheld, *Submission 40*, p. 2.

⁶⁶ Neil Vargesson, 'Thalidomide-induced limb defects: resolving a 50-year-old puzzle', *BioEssays*, Issue 31, p. 1327.

Professor Vargesson suggested to the committee that some of the internal organ damage that thalidomide survivors are experiencing later in life could be the result of maturation of their organs which were not fully functional due to in utero thalidomide damage.⁶⁷

- 2.35 Thalidomide survivors' submissions to the inquiry note they are experiencing health issues associated with their internal organs. For example, one thalidomide survivor submitted he was 'diagnosed as having a large oesophageal diverticulum and giant bulla of the lower lobe of the right lung.'⁶⁸ That survivor required surgery to rectify the diverticulum.⁶⁹ Another thalidomide survivors told the committee that he was born without a gall bladder, and his diet is constantly monitored as his liver is 'working overtime' to compensate for his absent gall bladder.⁷⁰
- 2.36 A number of thalidomide survivors submitted that they are experiencing heart problems.⁷¹ For example, one survivor who has Tetralogy of Fallot,⁷² reported having many open-heart surgeries and expects to have more surgery in the future.⁷³ That thalidomide survivor finds it difficult to walk long distances, in part, due to their heart condition.⁷⁴ Other thalidomide survivors also submitted that they are experiencing heart problems.

Nerve damage

- 2.37 One of thalidomide's less visible, but still harmful, impacts is damage to survivors' nerves. Michael Magazanik, Partner, Rightside Legal informed the committee that nerve damage was the initial indication of the damage thalidomide was to have

...the first shocking side-effect of thalidomide to become public was the slew of nerve damage that became apparent. Long before birth malformations were connected with the drug, it was apparent that [thalidomide] was doing really profound neurotoxic damage.⁷⁵

⁶⁷ Professor Vargesson, *Committee Hansard*, 31 January 2019, pp. 5–6.

⁶⁸ Name withheld, *Submission 50*, [p. 1].

⁶⁹ Name withheld, *Submission 50*, [p. 1].

⁷⁰ Name withheld, *Submission 57*, [p. 1].

⁷¹ Name withheld, *Submission 18*, p. 1; Name withheld, *Submission 42*, p. 3.

⁷² Note, Tetralogy of Fallot is a complex congenital heart condition comprised of four problems: a hole in the wall between the two lower chambers (ventricular septal defect); the valve between the heart and lungs is too narrow (pulmonary stenosis); overriding of the aorta; and thickening of the wall of the right heart chamber (right ventricular hypertrophy).

⁷³ Name withheld, *Submission 14*, [p. 1].

⁷⁴ Name withheld, *Submission 14*, [p. 3].

⁷⁵ Mr Michael Magazanik, Partner, Rightside Legal, *Committee Hansard*, 31 January 2019, p. 30.

- 2.38 Mr Lance Fletcher, President and Founder of Thalidomide Australia Incorporated has significant thalidomide induced damage to his cranial nerves six, seven and eight, and later experienced infections in cranial nerves ten and eleven.⁷⁶ Mr Fletcher explained the effect of cranial nerve damage for him was facial pain, trigeminal neuralgia, and impacts on his trapezius muscle. These impacts limited his ability to use a computer for long period, causes severe headaches, and reduction in his ability to function day to day. Ultimately, Mr Fletcher's nerve damage restricted his ability to work, leading to him leave a job that he loved, and was well paid, at the age of 49.⁷⁷
- 2.39 Thalidomide induced damage to nerves is a common experience amongst thalidomide survivors. Contributors to the inquiry described that nerve damage affects thalidomide survivors in varying ways, including: reducing their balance and smell;⁷⁸ causing weakness and tiredness;⁷⁹ creating skin sensations, such as pins and needles;⁸⁰ and causing significant pain.⁸¹
- 2.40 Nerve damage also caused by thalidomide appears to be worsening as thalidomide survivors age. The spouse of a thalidomide survivor told the committee that their thalidomide-affected partner experienced areas of numbness from their thalidomide damage which are 'spreading and growing larger.'⁸² There does not appear to be any research of thalidomide's nerve damage for Australia's thalidomide survivors, however research relating to overseas thalidomide survivors has been done.

Surgery

- 2.41 Some thalidomide survivors have sought to treat their congenital malformations and consequential health conditions through surgery.⁸³ The seriousness of thalidomide injuries has meant that some survivors have required multiple major surgeries throughout their life.⁸⁴ Surgery has been

⁷⁶ Mr Lance Fletcher, President and Founder, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 40.

⁷⁷ Mr Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 40.

⁷⁸ Lou, *Committee Hansard*, 31 January 2019, p. 49.

⁷⁹ Name withheld, *Submission 12*, p. 12.

⁸⁰ Name withheld, *Submission 40*, [p. 2]; Name withheld, *Submission 42*, [p. 1].

⁸¹ See, for example, Name withheld, *Submission 43*, [p. 2]; Name withheld, *Submission 43*, [p. 2]; Name withheld, *Submission 46*, [p. 3].

⁸² Name withheld, *Submission 10*, p. 4.

⁸³ Mandy, *Committee Hansard*, 2 November 2018, p. 18–19.

⁸⁴ Name withheld, *Submission 50*, [p. 1].

essential for many thalidomide survivors seeking to maintain their independence.⁸⁵

2.42 For some thalidomide survivors, surgical requirements of thalidomide survivors commenced early in their childhood. For example, one thalidomide survivor submitted that their first major surgery occurred at 14 months of age to straighten an arm which has been malformed.⁸⁶

2.43 Female thalidomide survivors have faced additional challenges of requiring breast reduction and mastectomy surgeries to reduce the strain on their bodies and to assist in maintaining their mobility and independence.⁸⁷ For survivors who have had mastectomy surgery, these procedures have been deemed 'elective', requiring those survivors to self-fund the procedure.⁸⁸ The Medicare Benefits Schedule includes three items for mastectomy and double mastectomy procedures, however non-therapeutic cosmetic surgery services do not attract Medicare benefits.⁸⁹ One survivor outlined the healthcare and functional need for double mastectomy surgery:

After much professional dialogue and thought, my plastic surgeon (six (6) years ago) agreed to my plea for a double mastectomy - purely for functionality purposes. The action of, and energy required, to put a bra on had become almost impossible for me. My toes, neck, back and shoulders had increased arthritis, which reduced my abilities to grip and manoeuvre my body and, my teeth were becoming too fragile to continue the act of getting into a bra. Additionally, my reach to my dinner plate was seriously impeded as, my one (1) usable hand, was not long enough to reach past my breasts to my food. I received no financial support from Medicare or my private health fund, despite written evidence provided by my general practitioner and surgeon! Mutilating my body in such a drastic way did not constitute as elective 'cosmetic surgery' for me!⁹⁰

2.44 Thalidomide survivors have required a range of different surgeries to treat their diverse thalidomide induced malformations and health conditions. Some of the surgeries required by survivors include:

- amputation of body components;⁹¹
- reconstruction ears and treatment of malformations;⁹²

⁸⁵ Name withheld, *Submission 42 – Attachment 2*, [p. 1].

⁸⁶ Name withheld, *Submission 45*, [p. 1].

⁸⁷ Name withheld, *Submission 11*, p. 4; Name withheld, *Submission 42*, [p. 2].

⁸⁸ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 6.

⁸⁹ Department of Health, answer to written question on notice, No. 5, [p. 5] (received 27 November 2018).

⁹⁰ Name withheld, *Submission 11*, p. 4.

⁹¹ Name withheld, *Submission 18*, [p. 1].

- operations to treat severe spinal scoliosis;⁹³
- operations to treat malformed arms;
- rotational osteotomy to treat malformations of the hip;⁹⁴
- eye lens replacement surgery;⁹⁵ and
- dental surgery to fix their damaged teeth.⁹⁶

2.45 For some survivors, options for corrective surgeries have been limited by the problems associated with their other health conditions, including abnormal physiology and osteoporosis.⁹⁷ Joanne, who previously worked as a graphic designer, explained to the committee how her thalidomide injuries restricted her options for surgery which led to her having to stop work:

I saw a hand surgeon who told me I could have surgery, but, as my anatomy is different from normal people, it was risky and he couldn't guarantee it would be successful. In fact, he said it could get worse. Seeing as I only have one so-called good arm, I wasn't prepared to take that risk. Also, I was strongly recommended against having the surgery by other doctors that had dealt with thalidomiders who had done the surgery and it wasn't a success. This forced me to stop work as the pain was unbearable, which put a massive financial strain on me and my husband.⁹⁸

2.46 The mother of a survivor submitted that her daughter's heart operations were ongoing to the extent their family decided to relocate to Brisbane to be near the Prince Charles Hospital.⁹⁹ Frequent and lengthy hospital visits to treat thalidomide injuries is a common experience amongst thalidomide survivors.¹⁰⁰

2.47 Many thalidomide survivors anticipate requiring further surgery in the future, and this is considered further in Chapter 3.

⁹² Name withheld, *Submission 9*, [p. 1]; Name withheld, *Submission 12*, [p. 2]; Name withheld, *Submission 13*, [p. 1]; Name withheld, *Submission 50*, p. 1; Name withheld, *Submission 57*, [p. 1]; Mandy, *Committee Hansard*, 2 November 2018, p. 18.

⁹³ Name withheld, *Submission 50*, p. 1; Name withheld, *Submission 27*, p. 1.

⁹⁴ Fiona, *Committee Hansard*, 31 January 2019, p. 17.

⁹⁵ Vicki, *Committee Hansard*, 31 January 2019, p. 17.

⁹⁶ Name withheld, *Submission 27*, [p. 1].

⁹⁷ Name withheld, *Submission 27*, p. 1; Name withheld, *Submission 41*, [p. 2].

⁹⁸ Joanne, *Committee Hansard*, 31 January 2019, p. 23–24.

⁹⁹ Name withheld, *Submission 54*, [p. 1].

¹⁰⁰ See, for example, UK Thalidomiders Campaign Team, *Submission 4*, p. 2; Name withheld, *Submission 40*, p. 1; Name withheld, *Submission 43*, [p. 1]; Name withheld, *Submission 45*, [p. 1]; Name withheld, *Submission 51*, [p. 1].

Ageing—early onset of age-related conditions and wear and tear

2.48 Thalidomide survivors told the committee that their bodies are 'failing' them and are wearing out.¹⁰¹ Whilst survivors are only aged between 53 – 58, the committee received evidence survivors experience symptoms of 'wear and tear' on their bodies that are normally associated with people in their 80s.¹⁰²

2.49 As noted earlier in this chapter, thalidomide survivors have sought to maintain their functionality and independence by using their bodies in unusual ways. Ms Newbronner explained how thalidomide survivors' health is changing with age:

...as thalidomide survivors reach late middle age, they're experiencing declining physical health, in particular secondary damage caused by the way they've had to use their bodies to compensate for their impairments. I think it's really important to understand that thalidomide embryopathy, whilst not progressive in the traditional sense, is not static.¹⁰³

2.50 The Thalidomide Group Australia told the committee that thalidomide survivors' '...disabilities and general health is being severely impeded upon as they age.'¹⁰⁴ This view was echoed by a number of other submissions to the inquiry that described the effects of thalidomide as accelerating, worsening, and magnifying, as survivors' age.¹⁰⁵ The committee was told that the 'early onset of aged related conditions in thalidomide survivors is 'clearly a major issue and requires urgent attention.'¹⁰⁶

2.51 Ageing can have a significant effect on thalidomide survivors' nervous system, as described by Professor McCredie:

...when the ageing process arrives for middle-aged thalidomiders, it hits a population that's already been severely depleted by the thalidomide experience in embryo. There are not enough nerve cells there to function properly, and so they get symptoms: nerves send the wrong messages, like pain, tingling and numbness; there's confusion of hot and cold sensations, and many other phenomena; or nerves may fail to function at all, and the part goes numb. So thalidomiders were robbed by thalidomide before birth: they were robbed of a population of nerve cells, and they were born with reduced numbers, without the normal buffer against any possible future damage. Thus, in middle age, thalidomide's minor nerve damage, combined with the age changes that are inevitable, combine to cause a

¹⁰¹ Name withheld, *Submission 9*, p. 2; Name withheld, *Submission 11*, p. 5.

¹⁰² UK Thalidomiders Campaign Team, *Submission 4*, [p. 2].

¹⁰³ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 3.

¹⁰⁴ Thalidomide Group Australia, *Submission 1*, p. 4.

¹⁰⁵ Name withheld, *Submission 20*, [p. 1]; Name withheld, *Submission 28*, p. 1; Name withheld, *Submission 37*, [p. 2]; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 45*, [p. 3].

¹⁰⁶ Professor Neil Vargesson, Information provided following appearing at the committee's public hearing on 31 January 2019, additional information received 6 February 2019, [p. 2].

profoundly debilitating sensory neuropathy, resulting in premature onset of old age.¹⁰⁷

2.52 As thalidomide survivors are challenged by early onset of ageing, survivors are also ageing differently from the general population and there is not an older generation of thalidomide survivors from which lessons can be learnt from.¹⁰⁸ Some of the premature ageing effects described in submissions made to the inquiry include:

- arthritic-related conditions;¹⁰⁹
- dental conditions, from using mouths instead of injured or absent hands and limbs;¹¹⁰ and
- increasing fatigue and weakness.

2.53 The severity of some survivors' early onset ageing indicates they will require access to aged care earlier than the general population. The Thalidomide Group Australia informed the committee that some survivors are already discussing accessing full-time care in the next few years of their life.¹¹¹ If this is the case, those survivors would be entering the aged care in their late 50s and early 60s.

2.54 The likelihood of requiring early access to aged care, and the associated limitation of their independence, was described by one thalidomide survivor as follows:

For 57 years, I have asked my body to perform every day tasks with my teeth; toes; leg deformities and, shortened arms with three (3) digits. I fight every day to maintain my independence. Reality will - sooner than later - dictate I enter permanent aged care at a much earlier age than for those midlife Australians who do not live with Thalidomide deformities. I have, on numerous occasions already, seriously considered moving into permanent care. I am acutely aware of, and am already grieving for, the loss of my independence.¹¹²

2.55 The committee considers thalidomide survivors likely aged care requirements in greater detail in Chapter 3.

Arthritic conditions

2.56 As a result of their thalidomide injuries, many submissions made to the inquiry describe that thalidomide survivors are experiencing arthritic

¹⁰⁷ Professor McCredie, *Committee Hansard*, 31 January 2019, p. 2.

¹⁰⁸ Ms Elizabeth Newbronner, *Submission 63*, pp. 3–4.

¹⁰⁹ Name withheld, *Submission 9*, p. 1.

¹¹⁰ Name withheld, *Submission 9*, p. 1.

¹¹¹ Thalidomide Group Australia, Answers to questions on questions on notice, 2 November 2018 (received 20 November 2018).

¹¹² Name withheld, *Submission 11.1*, [p. 1].

conditions affecting their: hands; wrist; toes; neck; back; shoulders; arms; knees; and hips.¹¹³ One thalidomide survivor told the committee they are experiencing 'significant arthritic deterioration' of their cervical spine.¹¹⁴ Fiona, a thalidomide survivor told the committee that she suffers from osteoarthritis of the spine which has resulted in spine curvature disorders, for which her surgeon is reluctant to operate on due to her osteoarthritis.¹¹⁵

2.57 Some submissions to the inquiry indicate that the arthritic-related pain experienced by thalidomide survivors is increasing.¹¹⁶ One thalidomide survivor summarised the affect arthritis has on her:

The arthritis in my body is chronic and severe, and now significantly limits my range of movement, affecting every aspect of my life.¹¹⁷

2.58 Ms Michelle French, who has previously accessed thalidomide survivors in her capacity as an occupational therapist, informed the committee that her assessments indicate survivors' secondary and tertiary health problems, including arthritis, are emerging as survivors age.¹¹⁸

2.59 For some thalidomide survivors, surgery is necessary to treat their arthritic conditions. As the time of submitting, one thalidomide survivor was waiting for a 'clean out and arthritic scraping' of their left shoulder, a procedure that individual has had three times previously on the same shoulder.¹¹⁹ As considered earlier in this chapter, another thalidomide survivor underwent a double mastectomy to, in part, slow down the progression of her arthritis.¹²⁰

2.60 The committee notes that the evidence presented to this inquiry regarding arthritis appears consistent with overseas research findings that thalidomide survivors are experiencing high rates of arthritic conditions.¹²¹

¹¹³ See: Name withheld, *Submission 9*, [p. 1]; Name withheld, *Submission 11*, p. 4; Name withheld, *Submission 17*, [p. 2]; Name withheld, *Submission 20*, [p. 1]; Name withheld, *Submission 32*, [p. 1]; Name withheld, *Submission 35*, p. 1; Name withheld, *Submission 39*, [p. 1]; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 48*, [p. 1].

¹¹⁴ Name withheld, *Submission 50*, [p. 1].

¹¹⁵ Fiona, *Committee Hansard*, 31 January 2019, p. 24.

¹¹⁶ Name withheld, *Submission 42 – Attachment 2*, [p. 1].

¹¹⁷ Name withheld, *Submission 42*, [p. 1].

¹¹⁸ Ms Michelle French, Director, Michelle French and Associates, *Committee Hansard*, 31 January 2019, p. 36.

¹¹⁹ Name withheld, *Submission 38*, p. 3.

¹²⁰ Name withheld, *Submission 42*, [p. 2].

¹²¹ Elizabeth Newbronner and Karl Atkin, 'The changing health of Thalidomide survivors as they age', *Disability and Health Journal*, vol 11, issue 2, p. 187.

Dental deterioration

- 2.61 Thalidomide survivors told the committee that, to compensate being unable to use their upper limbs, many survivors use their teeth to assist them to perform daily tasks. Some thalidomide survivors use their teeth to open jars, to get dressed, and even to hang out washing as their malformed arms are not able to assist them in performing those tasks.¹²²
- 2.62 Survivors use of their teeth to perform daily tasks has resulted in the degeneration of their teeth.¹²³ For example, one thalidomide survivor told the committee about the stress being placed on her teeth because of her injuries:
- My teeth are wearing down because I have to use them, turning the key to open my front door. I have no strength in my arms to do this.¹²⁴
- 2.63 Other survivors reported that their teeth have deteriorated to the extent that they require dental care, and in some case dental surgery.¹²⁵
- 2.64 Thalidomide survivors' evidence to the inquiry regarding use and deterioration of their teeth appears consistent with the experience of survivors overseas. For example, a study by the University of Heidelberg in Germany found that 88.8 per cent of thalidomide survivors used their teeth 'in order to compensate for the lack of grasping function of the hands'.¹²⁶ The report noted that opening bottles, carrying objects and operating levers damages the teeth, but also noted that thalidomide survivors may not be able to remove a regular dental prosthesis independently because they are unable to grasp it.¹²⁷
- 2.65 A recent survey of the health and wellbeing of thalidomide survivors in the United Kingdom found that '...just over a third have problems with dental health (often caused by the consequential damage of using teeth to dress, pick things up, open jars etc).'¹²⁸

Increasing fatigue and tiredness

- 2.66 Thalidomide survivors are experiencing increasing fatigue and tiredness as they age. Professor Janet McCredie told the committee that the pain

¹²² See, for example, Name withheld, *Submission 15*, [p. 3]; Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 6; Name withheld, *Submission 11*, p. 4; Name withheld, *Submission 42*, [p. 1].

¹²³ Name withheld, *Submission 9*, [p. 1].

¹²⁴ Name withheld, *Submission 15*, [p. 3].

¹²⁵ See, for example, Name withheld, *Submission 15*, [p. 3]; Name withheld, *Submission 18*, [p. 3]; Name withheld, *Submission 27*, [p. 1].

¹²⁶ Thalidomide Victims Association of Canada, *Submission 59—Attachment 2*, p. 45.

¹²⁷ Thalidomide Victims Association of Canada, *Submission 59—Attachment 2*, p. 46.

¹²⁸ UK Thalidomiders Campaign Team, *Submission 4*, [p. 2].

experienced by thalidomide survivors causes '...extreme fatigue and interferes with all their daily activities.'¹²⁹

- 2.67 Evidence submitted to the inquiry indicates that fatigue disrupts thalidomide survivors ability to work; walk long distances; and ability to travel to visit family.¹³⁰ Submissions to the inquiry noted that fatigue and tiredness is a general challenge for thalidomide survivors.¹³¹ The committee notes that evidence from overseas research has also identified fatigue as issue for thalidomide survivors.¹³²

Chronic pain

- 2.68 Thalidomide survivors often suffer from debilitating and chronic pain.¹³³ From the evidence provided to the inquiry, it is clear that survivors' lives are severely impacted by pain. The reduction and management of pain is a significant challenge for survivors, and their experiences with pain reduction techniques are diverse, complex and, at times, costly.
- 2.69 Submissions to the inquiry highlight a range of different pain types experienced by survivors and often survivors experience chronic pain throughout their bodies. Thalidomide survivors are also experiencing pain associated with nerve damage.¹³⁴ In some instances, survivors' pain is focussed on particular areas of the body, particularly areas of their initial thalidomide injury, or areas of their bodies which they have used to compensate for their thalidomide damage. One survivor told the committee that they have been, and continue to be, in pain every day.¹³⁵
- 2.70 Thalidomide survivors have also reported developing new forms of pain later in life. For example, a submitter to the inquiry described the pain and burning sensations which have developed in the feet of her thalidomide survivor

¹²⁹ Professor McCredie, *Committee Hansard*, 31 January 2019, p. 3.

¹³⁰ See, for example, Lou, *Committee Hansard*, 31 January 2019, p. 49; Name withheld, *Submission 9*, p. 1; Name withheld, *Submission 14*, p. 3; Name withheld, *Submission 17*, [p. 1].

¹³¹ See, for example, Name withheld, *Submission 20*, [p. 1]; Name withheld, *Submission 41*, [p. 1]; Name withheld, *Submission 42*, [pp. 3, 6]; Name withheld, *Submission 42—Attachment 1*, [p. 1]; Name withheld, *Submission 12*, [p. 2].

¹³² See, for example, Ms Elizabeth Newbronner, *Submission 63*, p. 1; UK Thalidomide Society, *Submission 61—Attachment 1*, pp. 4, 6.

¹³³ See, for example, Name withheld, *Submission 9*, p. 1; Name withheld, *Submission 16*, [p. 1]; Name withheld, *Submission 21*, p. 1.

¹³⁴ Name withheld, *Submission 10*, p. 4.

¹³⁵ Name withheld, *Submission 18*, [p. 3].

partner in recent years.¹³⁶ Another survivor told the committee that pains in his head and neck have recently become apparent.¹³⁷

- 2.71 Professor McCredie told the committee that findings of a substantial long-term study of thalidomide survivors in North Rhine-Westphalia, Germany suggest that survivors' late onset pain was from two primary causes:

...50 per cent of the pain was due to wear and tear on malformed joints and bones, entrapment, spondylosis and things like that, which occur in the normal community but are much worse in this [thalidomide survivor] community. But they said the other 50 per cent had the features of neurogenic pain—pain that was initiated in the nerve itself. That pain is extremely difficult, classically, to treat because it's a very persistent and a particularly strong character of pain.¹³⁸

- 2.72 Thalidomide survivors use a combination of treatments to manage their pain. Some of the pain management treatments described in evidence to the committee, include: prescription pain medications; chiropractic sessions; hydrotherapy; osteopathy; remedial massages; rest; and stretching exercises.¹³⁹ Pain management treatment can be essential to survivors' health and maintaining their mobility independence. Chapter 3 of this report considers in greater detail the importance of pain treatments.
- 2.73 From the evidence provided to the inquiry, it is clear that thalidomide survivors' experience with chronic pain is reducing their ability to perform a range of everyday tasks and live independently. Severe and chronic pain restricts thalidomide survivors: ability to work; to sleep or get out of bed in the morning; play with their children; cook; and use public transport.¹⁴⁰
- 2.74 Performing everyday tasks can also result in inordinate pain for survivors. For example, one submitter told the committee that routine air travel would result in their thalidomide survivor spouse being bedridden for up to a week.¹⁴¹

Accidents and injuries

- 2.75 As a result of thalidomide induced birth defects and chronic health conditions, thalidomide survivors may experience accidents and injuries. Survivors told

¹³⁶ Name withheld, *Submission 17*, [p. 1].

¹³⁷ Name withheld, *Submission 40*, [p. 2].

¹³⁸ Professor McCredie, *Committee Hansard*, 31 January 2019, p. 5.

¹³⁹ See, for example, Name withheld, *Submission 9*, p. 1; Name withheld, *Submission 50*, p. 1; Name withheld, *Submission 43*, pp. 1–2.

¹⁴⁰ See, for example, Name withheld, *Submission 17*, [p. 1]; Name withheld, *Submission 21*, p. 2; Name withheld, *Submission 27*, [p. 1]; Name withheld, *Submission 41*, [p. 1]; Name withheld, *Submission 64*, p. 1. Name withheld, *Submission 28*, [p. 1].

¹⁴¹ Name withheld, *Submission 21*, p. 4.

the committee that thalidomide injuries caused them to experience issues with their balance, and in some cases fall over.¹⁴²

- 2.76 In one case, a thalidomide survivor fell over whilst on public transport, and due to their arm malformations was unable to break the fall and consequently broke their nose.¹⁴³ Another survivor told the committee:

Last year I had a fall and as I can't stop myself from falling I hit my head on concrete pavers I broke my nose in three places and did significant damage to both Patella's and Clavicle. I went to Flinders Medical Centre, and after being there for over 5 hours and after having X-Rays was told to go home and see my GP on Monday morning. The doctors didn't understand Thalidomide disabilities and didn't understand the severity of my conditions. I still haven't totally recovered from this fall, either physically or emotionally, and sometimes have anxiety about going to unfamiliar places in case I fall again.¹⁴⁴

- 2.77 Rick, a thalidomide survivor, told the committee that every time he falls over he breaks his femur, which is inoperable due to his congenital malformations. On one occasion, this resulted in Rick being hospitalised for approximately two months.¹⁴⁵
- 2.78 Some female survivors told the committee that due to their functional limitations they had experienced burns to their breasts whilst cooking.¹⁴⁶

Psychosocial and mental health impacts

- 2.79 Thalidomide survivors often have severe physical impairments. They face deteriorating health conditions, chronic pain, and the impacts of early ageing. Survivors live with these challenges every day. These ongoing physical challenges also have psychosocial impacts for thalidomide survivors, which have in some cases resulted in serious mental health issues. Survivors have experienced the psychosocial and mental health impacts of thalidomide, alongside their physical injuries, throughout their lives. These impacts are evidence through survivors' experiences of depression, anxiety, being bullied and social isolation.
- 2.80 Ms Newbronner, submitted there are 'two primary reasons for poor mental health' amongst thalidomide survivors:

¹⁴² See, for example, Name withheld, *Submission 14*, [p. 1]; Name withheld, *Submission 18*, [p. 1]; Name withheld, *Submission 32*, [p. 1]; Name withheld, *Submission 40*, [p. 3]; Name withheld, *Submission 42*, [p. 3].

¹⁴³ Name withheld, *Submission 20*, [p. 1].

¹⁴⁴ Name withheld, *Submission 42*, [p. 2].

¹⁴⁵ Rick, *Committee Hansard*, 2 November 2018, p. 15.

¹⁴⁶ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 6; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 42—Attachment 2*, [p. 1].

...the cumulative impact of living with a rare disability, and in particular the sense of 'being different' which this engenders; and the emotional impact of further loss of function, associated with secondary health problems. However, how these experiences affect people and how they make sense of them, is influenced by both individual circumstances (e.g. family responses or life events) and the wider societal context (such as access to care and support, in addition to access to social networks, labour markets, housing and financial resources).¹⁴⁷

- 2.81 Dr Debra Kennedy told the committee that there are several studies which demonstrate that thalidomide survivors experience increase rates of mental health disorders, and that mental health issues are likely to increase as survivors age and face new challenges.¹⁴⁸ For example, a 2015 study of thalidomide survivors in Germany found that mental health disorders were twice as common amongst thalidomide survivor respondents that they were for the general German population.¹⁴⁹ A later 2017 study of thalidomide survivors in Germany found that 47 per cent of the study participants had at least one mental health disorder in the four weeks prior to the study.¹⁵⁰ A 2015 report on thalidomide survivors living in the United Kingdom found that over half of the respondents indicated their emotional wellbeing was worse, or much worse, than it was five years previously.¹⁵¹

Depression

- 2.82 Evidence to the inquiry describes the experiences of thalidomide survivors in struggling with poor mental health, including being diagnosed and treated for depression.¹⁵² For some survivors, it is apparent that their experience with depression is a direct consequence of their thalidomide-induced disabilities.
- 2.83 One survivor described the depression she experienced early in life, and the difficulty she faced accessing counselling services:

After completing my Higher School Certificate (HSC) I spiralled into a very deep [clinical] depression. I felt I had no future. I had completed my secondary school studies - but for what? I could not nominate for any

¹⁴⁷ Ms Elizabeth Newbronner, *Submission 63*, p. 3.

¹⁴⁸ Dr Debra Kennedy, *Committee Hansard*, 31 January 2019, p. 2.

¹⁴⁹ Federal Health Centre North Rhine Westphalia, *Damage to Health, Psychosocial Disorders and Care Requirements of Survivors in North Rhine Westphalia from a Long-Term Perspective*, 2015, p. 95.

¹⁵⁰ Alexander Niecke, Klaus Peters, Christina Samel, Kristin Forster, Markus Lungen, Holger Pfaff, Christian Albus, 'Mental Disorders in People Affected by Thalidomide', *Dtsch Arztebl Int*, vol. 114, issue 10, 2017, p. 171.

¹⁵¹ The Thalidomide Trust, *Changing Lives – The Health and Wellbeing of Thalidomide Survivors in Middle Age*, 2015, p. 44.

¹⁵² See, for example: Name withheld, *Submission 41*, p. 2; Name withheld, *Submission 11*, p. 3; Name withheld, *Submission 50*, p. 1.

university courses as I had no way of getting to and from any campus. Who would want to employ me? ... What could I do anyway?

I sought professional counselling, but it sapped me of my [limited] emotional reserves explaining my life and particularly, my Thalidomide disabilities. I could find no-one for whom I did not have to put them at ease - in order for me to begin exploring my depression.¹⁵³

- 2.84 The committee received evidence that some survivors have had suicidal ideations, and that suicidal ideations amongst survivors is increasing.¹⁵⁴ One thalidomide survivor shared her experience with the committee:

I am one who has considered suicide. I was going to do it in my car. I was going to just drive. I would survive a work day, and then I would contemplate driving my car into a tree. And what stopped me was my GP once saying to me, 'Please don't ever try because I've had people that've done it, and they've survived and been worse off.' I thought: all I need to be is a quadriplegic on top of this!¹⁵⁵

Bullying and harassment

- 2.85 For thalidomide survivors who have experienced bullying and harassment, often due to their visible physical thalidomide injuries, there has been a significant emotional toll.¹⁵⁶ Contributors to the inquiry described survivors' experiences with being verbally bullied and physically bullied during their schooling and formative years as: 'torture';¹⁵⁷ 'extreme';¹⁵⁸ and 'relentless'.¹⁵⁹

- 2.86 A survivor told the committee that the 'endless' and 'relentless' verbal and physical bullying they experienced in school contributed to their development of a speech impediment.¹⁶⁰ The nick name 'half head' was used to bully one thalidomide survivor in high school:

...the bigger boys would grab me by my shirt bring me up to their face contort their mouth and laugh and call me half head. After this it caught on through the school and I could be anywhere in the school and I would hear 'half head'. Because I was deaf in my right ear I had no idea where it

¹⁵³ Name withheld, *Submission 11*, p. 3.

¹⁵⁴ See, for example, Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 2; Name withheld, *Submission 25*, p. 5; Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

¹⁵⁵ Mary, *Committee Hansard*, 2 November 2018, p. 22.

¹⁵⁶ See, for example, Name withheld, *Submission 12*, [p. 1]; Barbara-Ann, *Committee Hansard*, 2 November 2018, p. 14; Name withheld, *Submission 18*, [p. 1]; Name withheld, *Submission 20*, p. 1; Name withheld, *Submission 40*, [pp. 2–3]; Name withheld, *Submission 45*, [p. 2]; Name withheld, *Submission 50*, [p. 2]; Name withheld, *Submission 45*, p. 2. Name withheld, *Submission 131*, p. 1.

¹⁵⁷ Name withheld, *Submission 36*, p. 1.

¹⁵⁸ Lance, *Committee Hansard*, p. 16.

¹⁵⁹ Name withheld, *Submission 42*, [p. 1].

¹⁶⁰ Name withheld, *Submission 42*, [p. 1].

was coming from but it was the most awful feeling. I lived with this daily and it got worse. I learned to stand up for myself and I would find myself fighting sometimes.¹⁶¹

- 2.87 The experience of physical fights arising from bullying in school was also shared by other thalidomide survivors.¹⁶² The educational outcomes of at least one survivor were adversely impacted by bullying:

School was the worst, I was called names, picked on, laughed and starred at and talked about behind my back. I had no friends! I rejected school altogether and as a result fought all the time with my parents because I did not want to go. There was not one day that I didn't get into a fight at school because I was no longer able to tolerate all the bullying. I cried a lot at night without my parents knowing and I pretended to go to school without my parents knowledge and my reading and writing skills lack because of this.¹⁶³

- 2.88 Some thalidomide survivors provided evidence to the committee that harassment and bullying has occurred later in life, and in some cases is ongoing.¹⁶⁴ One survivor provided an example of the abuse they have experienced later in life:

One of my worst experiences of bullying was being "pissed on" by a drunk patron in the toilets at the Beaches Hotel whilst his drunk mate looked on and laughed. I was so shocked I didn't know what to do or say. Fortunately, such extreme instances of abuse have been few. Most bullying has been directed at how I look and it was often the intention of the individual to make fun of me rather than cause physical harm.¹⁶⁵

- 2.89 Patricia told the committee that she is still bullied, and this can occur as soon as she leaves home:

I haven't even mentioned the bullying that I have endured—and still get, the minute I leave the safety of my home. People say the most horrid things to me as they walk past me. There was a time when I never left my house, for many, many months, as I did not want to get bullied by strangers.¹⁶⁶

Medical practitioners' dismissive and abusive behaviour

- 2.90 Some members of the medical fraternity were dismissive or insensitive to the parents of thalidomide survivors when they first realised that their child had

¹⁶¹ Name withheld, *Submission 40*, [p. 2].

¹⁶² Name withheld, *Submission 13*, p. 1.

¹⁶³ Name withheld, *Submission 43*, p. 1.

¹⁶⁴ See, for example: Nola, *Committee Hansard*, 2 November 2018, p. 20: Name withheld, *Submission 13*, [p. 2]; Name withheld, *Submission 14*, p. 4; Name withheld, *Submission 21*, p. 1; Name withheld, *Submission 23*, p. 1; Name withheld, *Submission 50*, [p. 3].

¹⁶⁵ Name withheld, *Submission 50*, [p. 3].

¹⁶⁶ Patricia, *Committee Hansard*, 31 January 2019, p. 22.

been born with a disability.¹⁶⁷ Thalidomide survivors also told the committee about a variety of concerning behaviours by health practitioners over the course of their lives. In some cases, thalidomide survivors reported behaviour that lacked empathy.

- 2.91 One thalidomide survivor told the committee about encounters with health practitioners when she was younger:

In 1967, I remember being carried into a doctor's room. He looked me up and down and said to my mum: 'Yep; she's a cripple. Now get out of my office.' In 1970, doctors wrote in reports that I had a 'beautiful smile', but that my aims in life were commendable but ridiculous.¹⁶⁸

- 2.92 The survivor went on to explain that, sadly, these kinds of comments were not confined to history. In 2002, she advised she had taken her sick daughter to see a specialist. When the specialist could not find anything wrong with her daughter, he added:

Have you ever thought she is just reacting to having a mother that looks like you?¹⁶⁹

- 2.93 In 2010, a radiologist told a thalidomide survivor:

You are too weird; I don't know what I am looking at. Go away.¹⁷⁰

- 2.94 This behaviour is consistent with the bullying and harassment that thalidomide survivors have been forced to endure throughout their lives. Another possible reason for such poor treatment is that medical professionals have little knowledge about thalidomide or its effects.

Social wellbeing

- 2.95 Contributions to this inquiry convey how for thalidomide survivors living with significant physical impairments, their social engagement and acceptance has been diminished. Thalidomide survivors described psychological effects of isolation and social exclusion as a result of their reduced mobility, or their requirements for assistance when outside of their places of residence.¹⁷¹

- 2.96 Thalidomide survivors' bodies are often plainly different, and survivors' submissions show that this difference has not always been dealt with sensitively by others. For example, one survivor described the sense of shame she felt as a result of her thalidomide injuries:

I could not even utter the word '*Thalidomide*' until I was well into my 20s, as my condition was spoken about in hushed tones around me, which had

¹⁶⁷ See, for example, Susan, *Committee Hansard*, 31 January 2019, p. 22.

¹⁶⁸ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

¹⁶⁹ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

¹⁷⁰ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

¹⁷¹ Name withheld, *Submission 15*, p. 2; Name withheld, *Submission 8*, p. 1.

me believing Thalidomide was a 'bad word' and, one for which I felt shame.¹⁷²

- 2.97 One thalidomide survivor described feeling worthless: 'I felt and still do, sometimes, feel like a second class citizen. Not equal or worth anything.'¹⁷³
- 2.98 Survivors' negative social experiences were described to the committee in a number of ways, including being 'whispered about' or 'pointed at' or being asked as an adult whether they are a 'thalidomide baby'.¹⁷⁴ For some survivors, their social experiences led to them feeling of social isolation in their formative years, which was described as: not feeling 'normal'; unable to 'fit in'; or that they were being 'stared at'.¹⁷⁵ One thalidomide survivor explained that, whilst their childhood was very happy, they began to experience social isolation at the age of 18 from reduced engagement with friends; the impact of this was described as '...nothing short of hopelessness and complete devastation.'¹⁷⁶

Committee view

- 2.99 As described at the beginning of this of this chapter, it is clear from the evidence provided to the committee that the health impacts of thalidomide for survivors are wide ranging and are often catastrophic. The committee recognises that the congenital malformations associated with thalidomide embryopathy are significant and diverse. For survivors, an immediate consequence of the thalidomide-induced congenital malformations are complex and multiple health conditions, including psychosocial and mental health impacts. The committee recognises that thalidomide survivors have to live with the impairments caused by both congenital malformations and consequential health impacts every day.
- 2.100 The committee considered evidence during the inquiry which clearly describes that the health impacts of thalidomide on survivors is ongoing. Contributors to the inquiry outlined how survivors outcomes are changing for a range of reasons. This evidence clearly indicates that as thalidomide survivors age, their congenital malformations and chronic health outcomes are deteriorating. This deterioration is exacerbated by the additional wear and tear placed on their bodies by necessarily contorting their bodies to perform daily tasks. The committee considers the evidence regarding thalidomide survivors evolving health requirements is particularly compelling.

¹⁷² Name withheld, *Submission 11*, p. 2.

¹⁷³ Name withheld, *Submission 15*, p. 1.

¹⁷⁴ See, for example, Joanne, *Committee Hansard*, 31 January 2019, p. 23; Name withheld, *Submission 37*, [p. 1]; Name withheld, *Submission 16*, [p. 1]; Mary, *Committee Hansard*, 2 November 2018, p. 16.

¹⁷⁵ Name withheld *Submission 15*, p. 2.

¹⁷⁶ Name withheld, *Submission 8*, p. 1.

- 2.101 From examining material for this inquiry, the committee considers there is inadequate knowledge regarding Australia's thalidomide survivors' health conditions. The committee is particularly concerned that survivors' health conditions are deteriorating, and there is not a coordinated body of knowledge to inform an understanding of Australia's thalidomide survivors' health requirements.
- 2.102 The committee recognises that the thalidomide survivors who are alive today have survived the severely damaging in utero effects of thalidomide, have survived the mortality associated with thalidomide embryopathy, particularly in the first year of life, and have survived the health complications associated with thalidomide injuries. The profound health impacts of thalidomide for survivors cannot be reversed, however the committee recognises that for survivors' complex health conditions to be ameliorated, intensive and specialised treatments and supports are required. As survivors age, their need for intensive and specialised supports can reasonably be anticipated to increase.

Lifelong consequences of thalidomide injuries

- 2.103 Thalidomide survivors' often severe physical impairments have a profound impact on their day-to-day quality of life. Whilst thalidomide survivors strive to maintain their independence and dignity—survivors have made adaptations in their lives to support this—it is evident that there are lifelong consequences of thalidomide injuries.
- 2.104 Due to their injuries, thalidomide survivors face challenges performing routine tasks, have faced challenges in accessing education and participating in the workforce, and experienced the financial burdens of forced early retirements and the high costs of healthcare and disability supports. Dr Kennedy described the complexity of challenges faced by thalidomide survivors:

While many individuals have done remarkably well in achieving their potential, particularly in terms of education and career, despite huge physical difficulties and societal and practical barriers, it's apparent that many still face significant challenges and have to deal with chronic physical and psychological problems, often without specialist assistance from healthcare professionals who have expertise and experience in dealing with their specific needs.¹⁷⁷

Difficulty performing everyday tasks

- 2.105 Thalidomide survivors submitted to the committee that their health conditions and impairments make performing everyday tasks difficult. The extent to which survivors face challenges performing everyday tasks is contingent on the severity of their impairments and health conditions. As one of the most

¹⁷⁷ Dr Debra Kennedy, *Committee Hansard*, 31 January 2019, p. 2.

common thalidomide-induced birth defects is phocomelia, many survivors are unable to easily do tasks that would ordinarily be performed with their limbs.

2.106 For thalidomide survivors experiencing chronic pain and arthritic conditions, performing tasks that involve other parts of their bodies, particularly their feet is difficult.¹⁷⁸ Thalidomide survivors' impairments make it difficult for them to perform a wide range of everyday activities, including:

- walking or standing for long periods (noting some survivors are unable to walk or stand at all);¹⁷⁹
- sleeping due to chronic pain;¹⁸⁰
- using public transport;¹⁸¹
- showering or toileting;¹⁸²
- dressing;¹⁸³
- meal preparation;¹⁸⁴
- using public transport;¹⁸⁵
- hanging out washing;¹⁸⁶
- raising children;¹⁸⁷
- shopping;¹⁸⁸ and
- socialising.¹⁸⁹

2.107 Patricia, who has severe thalidomide-induced upper limb malformations, told the committee that she requires assistance with day-to-day tasks:

Living in pain 24/7 is horrid and debilitating. I need help dressing, toileting, eating, opening doors, getting from A to B—basically, I need help for everything I do. It is very tiring being a thalidomide survivor.

¹⁷⁸ Name withheld, *Submission 10*, [p. 4].

¹⁷⁹ See, for example, Nola, *Committee Hansard*, 2 November 2018, p. 20; Fiona, *Committee Hansard*, 31 January 2019, p. 24; Name withheld, *Submission 10*, [p. 4]; Name withheld, *Submission 14*, p. 3; Name withheld, *Submission 27*, p. 1; Name withheld, *Submission 40*, [p. 3]; Name withheld, *Submission 41*, [p. 2].

¹⁸⁰ See, for example, Name withheld, *Submission 21*, [p. 2]; Name withheld, *Submission 45*, [p. 1].

¹⁸¹ Name withheld, *Submission 41*, [p. 1].

¹⁸² Name withheld, *Submission 16*, [p. 2].

¹⁸³ Name withheld, *Submission 30*, [p. 1].

¹⁸⁴ Name withheld, *Submission 30*, [p. 1].

¹⁸⁵ Name withheld, *Submission 41*, [p. 2].

¹⁸⁶ Name withheld, *Submission 41*, [p. 2].

¹⁸⁷ Suanne, *Committee Hansard*, 31 January 2019, p. 48.

¹⁸⁸ See, for example, Thalidomide Group Australia, *Submission 1*, p. 33; Name withheld, *Submission 10*, p. 5.

¹⁸⁹ See, for example, Name withheld, *Submission 27*, p. 1; Mary, *Committee Hansard*, 2 November 2018, p. 16; Name withheld, *Submission 42*, p. 1; Name withheld, *Submission 11*, p. 4.

Everything I do is a struggle, and I don't get a minute to escape what thalidomide did to me.¹⁹⁰

- 2.108 Thalidomide survivors' submissions emphasise that performing routine tasks is becoming increasingly difficult for them due to their chronic health issues worsening, such as arthritis and stiffness, or chronic pain making it difficult to concentrate.¹⁹¹
- 2.109 As thalidomide survivors' impairments and health conditions increasingly limit their functionality, survivors are often becoming more reliant on assistance from their immediate family members for day-to-day support.¹⁹²

Lost life opportunities and freedoms

- 2.110 There are some life opportunities and freedoms which are extremely difficult for thalidomide survivors to obtain, and some opportunities of which survivors have been robbed. Some survivors have been unable to have children, work in their preferred occupations, or engage in leisure activities.¹⁹³
- 2.111 One thalidomide survivor told the committee of the opportunities that they had lost as result of thalidomide:

It stole from me so many of the simple childhood opportunities that should have been mine, such as playing ball, skipping rope, playing marbles, even going to the bathroom by myself. In my teenage years, it stole my self-esteem, my ability to date, to play sport, to blend with my peers. As a young woman, Thalidomide continued to steal. I was unable to do simple house chores, apply for most jobs, study most degrees, travel freely, or dress and carry my babies.¹⁹⁴

- 2.112 Several submitters to the inquiry told the committee that survivors have never been able to return a hug from a loved one.¹⁹⁵ Other survivors have struggled to find, or have never had, a romantic partner.¹⁹⁶

Impact on parents, family members and carers

- 2.113 Whilst thalidomide injuries are experienced by survivors, the impacts of those injuries are also borne by survivors' families. This is particularly true for those

¹⁹⁰ Patricia, *Committee Hansard*, 31 January 2019, p. 22.

¹⁹¹ See, for example, Name withheld, *Submission 50*, [p. 4]; Name withheld, *Submission 42*, p. 2; Name withheld, *Submission 39*, [p. 1].

¹⁹² Name withheld, *Submission 46*, p. 2.

¹⁹³ See, for example, Name withheld, *Submission 6*, p. 2; Name withheld, *Submission 46*, p. 3.

¹⁹⁴ Name withheld, *Submission 6*, p. 2.

¹⁹⁵ See, for example, Name withheld, *Submission 10*, [p. 4]; Name withheld, *Submission 14*, [p. 4]; Name withheld, *Submission 21*, [p. 4]; Name withheld, *Submission 36*, [p. 3].

¹⁹⁶ See, for example, Lance, *Committee Hansard*, 31 January 2019, p. 6; Andrew, *Committee Hansard*, 31 January 2019, p. 6; Name withheld, *Submission 12*, p. 1.

closest to survivors, usually their parents, partners; and children. Evidence received during this inquiry shows that families have experienced the emotional toll of thalidomide alongside their thalidomide survivor loved ones, and often experienced emotional trauma of their own. The family members of thalidomide survivors have made extraordinary commitments to contribute to caring for survivors.

Trauma and guilt of thalidomide survivors' parents

2.114 For the parents of thalidomide survivors, the birth of their thalidomide-affected child was a particularly difficult experience. The mother of one thalidomide survivor described the birth of her son as a '...trauma from which I have never recovered.'¹⁹⁷ One thalidomide survivor told the committee of the negative impact that her own birth had on her parents:

...while my life was just beginning, my parent's lives had been thrown into a spiral of shock, disbelief, and guilt. It wasn't supposed to be like this for them ... they were expecting a healthy baby that would complete their new family, and that would go on to lead a normal and happy life.¹⁹⁸

2.115 Other evidence received by the committee described a lifetime guilt experienced by the parents of survivors, particularly mothers, as result of taking a drug which would, unknown to them, have a severe impact on their child.¹⁹⁹ Mr Fletcher indicated that relationship strain was a common experience for the parents of thalidomide: 'There were a lot of divorces, people shooting through and parents not coping. A lot of kids didn't make it through the first year.'²⁰⁰

2.116 In some cases, the difficult experience of giving birth to a severely injured child may have been exacerbated by cruel and ill-considered comments from hospital staff. The mother of one thalidomide survivor was reportedly told by doctors that 'the kindest thing you can do for her is smother her while she is sleeping.'²⁰¹ Another mother was reportedly told to send her child to an 'institution and forget about him'.²⁰²

¹⁹⁷ Name withheld, *Submission 25*, p. 2.

¹⁹⁸ Name withheld, *Submission 6*, p. 1.

¹⁹⁹ See, for example, Barbara-Ann, *Committee Hansard*, 2 November 2018, p. 14; Thalidomide Group Australia, *Submission 1*, p. 36. Name withheld, *Submission 11*, p. 1; Name withheld, *Submission 12*, [pp. 1], [2]; Name withheld, *Submission 13*, [pp. 1, 2]; Name withheld, *Submission 14*, p. 1; Name withheld, *Submission 16*, p. 2; Name withheld, *Submission 20*, p. 1; Name withheld, *Submission 36*, [p. 2]; Name withheld, *Submission 38*, p. 6. Name withheld, *Submission 39*, p. 1; Name withheld, *Submission 42*, [pp. 5, 6].

²⁰⁰ Mr Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 44.

²⁰¹ Name withheld, *Submission 14*, p. 1.

²⁰² Name withheld, *Submission 25*, p. 2.

2.117 Given the immeasurable impact thalidomide has had on the lives their parents, many survivors have called for any apology specifically in recognition of their parents, many of whom are now deceased.²⁰³

Carer responsibilities

2.118 As thalidomide survivors were growing up, they often had intensive care requirements which were taken on by their parents. Parents provided care to their thalidomide-affected children in variety of ways, including: assisting with toileting;²⁰⁴ 'assisting with all physical tasks' and providing emotional support.²⁰⁵

2.119 As adults, thalidomide survivors have sought to live independently. However for daily tasks that survivors' impairments make difficult, survivors' family members have continued to provide assistance. For example, Andrew told the committee that he will need help to manage when his elderly parents pass away.²⁰⁶

2.120 In some cases, immediate family members of thalidomide survivors have also become their full-time carers.²⁰⁷ In doing so, those family members have made considerable personal commitments and in some cases sacrifices, including stopping work:

In 2006 I stopped fulltime work to be my wife's fulltime carer, yes, it was my choice, but with no funding and [as her] mum now [too] old [sic] to physically help [her] we had no other choice, as each time we asked the government for help we were told 'we do not fund Thalidomide survivors'. ... My concerns were mainly for [my wife's] safety as she was unable to unlock the doors on our home, I was frightened [of her] dislocating her hip again while dressing (happens from time to time when your feet are your hands and you are trying to put a bra or top on). On the nights I worked, she went to bed fully clothed and without eating more than a soggy sandwich that I had made many hours before. I could no longer stand seeing the danger I was putting her in every time I left her to work on my long shift, so I gave up work.²⁰⁸

2.121 One thalidomide survivor told the committee that her daughter became her fulltime carer when her husband was no longer able to fulfil that role. To do

²⁰³ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 1.

²⁰⁴ Name withheld, *Submission 15*, [p. 2].

²⁰⁵ Name withheld, *Submission 20*, p. 1.

²⁰⁶ Andrew, *Committee Hansard*, 31 January 2019, p. 17.

²⁰⁷ See, for example, Barbara-Ann, *Committee Hansard*, 2 November 2018, p. 14; Amanda, *Committee Hansard*, 2 November 2018, p. 19; Name withheld, *Submission 21*, pp. [1–3]; Name withheld, *Submission 38*, pp. [2–3].

²⁰⁸ Name withheld, *Submission 21*, pp. 1–2.

this, her daughter had to relocate from interstate and leave behind her satisfying employment, home, and friends.²⁰⁹

- 2.122 Some carers of thalidomide survivors' also appear to be experiencing adverse psychosocial impacts as a result of the intense care requirements leading to social isolation.²¹⁰

Education, workforce participation and forced early retirement

- 2.123 Thalidomide survivors' physical impairments have created permanent barriers in their access to education and employment. Many survivors have participated in the workforce, however, in recent years survivors have been forced to retire as a result of their deteriorating thalidomide injuries and worsening chronic health conditions.

Education

- 2.124 For some accessing education was a challenge as there were not appropriate supports available at local schools to support their additional requirements.²¹¹ A thalidomide survivor described this experience in her submission:

I had to be able to go to the toilet by myself before I could attend my local public school. I had to be able to feed myself at school because there were no Teachers Aides to help me.²¹²

- 2.125 Some survivors told the committee that schools would simply not accept them as a student based on their disabilities. Patricia told the committee that 'In 1970, no government school in all of Brisbane would accept me. Mum had to get a job to pay for my private school education.'²¹³ The mother of a thalidomide survivor described that it was a 'battle' to get her thalidomide-affected daughter into a mainstream school, and that this proved 'extremely difficult as disabled children did not attend normal schools, they went to crippled children's homes and alike.'²¹⁴
- 2.126 Lance told the committee that his thalidomide injuries directly impacted on his ability to study: 'My ability to study was affected because of my deafness—many times I tried.'²¹⁵ The mother of a thalidomide survivor told the

²⁰⁹ Name withheld, *Submission 38*, p. 4.

²¹⁰ Name withheld, *Submission 21*, p 3.

²¹¹ Name withheld, *Submission 15*, p. 2.

²¹² Name withheld, *Submission 15*, [p. 2].

²¹³ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

²¹⁴ Name withheld, *Submission 54*, p. 1.

²¹⁵ Lance, *Committee Hansard*, 31 January 2019, p. 18.

committee that her son dropped out of a course in horticulture because he was lonely and started drinking.²¹⁶

2.127 As identified in the previous section of this chapter, the bullying of thalidomide survivors during their school years, in some cases, led to diminished educational outcomes for the those survivors.

Workforce participation

2.128 Many thalidomide survivors have faced challenges in accessing and remaining in the workforce, due to physical limitations imposed by their injuries, and the consequential deterioration of their health conditions which causing pain.²¹⁷

2.129 Some survivor told the committee that they were unable to secure a fulltime position in their chosen profession, due to their physical impairments, and that this had both a negative financial impact and an emotional impact.²¹⁸

2.130 Other thalidomide survivors' submissions indicate they have been discriminated against when applying for employment, due to misconceptions and prejudices regarding their appearance with visible congenital malformations.²¹⁹ For Joanne, a thalidomide survivor, experience with employment discrimination began when she tried to get her first job:

As a young adult, my first experience of trying to get a job was very traumatic. It was a sales assistant job at Woolworths in Pitt Street, Sydney. I was filling out the forms when the person working there said, 'Sorry, you can't apply for this job.' I replied, 'But why?' Their response was, 'Because you might be working in the deli, and we can't have you working with food.' I was so upset that I called my sisters, who went straight there to stand up for me and tell them off. This destroyed my confidence and self-esteem, and it took me a long time to get over it.²²⁰

2.131 When thalidomide survivors were able to enter the workforce they were often forced to retire early as a result of deterioration of their thalidomide injuries and health conditions.²²¹ Andrew, a thalidomide survivor, told the committee of his experience losing his job:

I lost the job I used to have, because my vision got worse. I couldn't see properly. I couldn't see far away. Then I was unable to continue working. I

²¹⁶ Name withheld, *Submission 12*, [p. 1].

²¹⁷ Name withheld, *Submission 9*, pp. 2–3.

²¹⁸ Name withheld, *Submission 9*, p. 1.

²¹⁹ Name withheld, *Submission 41*, p. 1; Name withheld, *Submission 38*, [p. 3].

²²⁰ Joanne, *Committee Hansard*, 31 January 2019, p. 23.

²²¹ See, for example, Alice, *Committee Hansard*, 2 November 2018, p. 16; Name withheld, *Submission 6*, p. 2; Name withheld, *Submission 28*, [p. 1].

wanted to try to work as a labourer for a company but I couldn't because of work, health and safety concerns.²²²

2.132 Forced early retirement appears to be a common experience amongst the thalidomide survivor cohort. The committee received evidence that survivors had to retire early from careers in various fields, including: academia; the Commonwealth Public Service; graphic design and customer service.²²³ A 2016 report from the UK Thalidomide Trust found that, of the United Kingdom survivors studied: 41 per cent were unable to work due to health problems; 15.4 per cent were employed full-time; and 22 per cent worked part-time.²²⁴

2.133 As noted above, those that care for thalidomide survivors also face challenges in remaining in the workforce. The spouses of some thalidomide told the committee that they had left their employment to care for their thalidomide-affected partner.²²⁵

Financial wellbeing

2.134 The committee heard that the financial wellbeing of survivors has suffered as a result of their thalidomide injuries. Thalidomide injuries have meant that some survivors have had their education disrupted and have experienced difficulty accessing and remaining in the workforce. Many lack the financial resources to meet significant out-of-pocket costs associated with managing their thalidomide injuries. The risk to thalidomide survivors' financial wellbeing is exemplified in the submission of a survivor who was forced to retire early and worried about no longer being able to afford the family home:

Due to my body deteriorating, I was forced into an early retirement at the age of 49 and lost the opportunity to earn good money to pay off my loan. Unfortunately, my husband who has helped me every day for the last 39 years, was also forced into medical retirement thus putting us under financial strain. We don't want to lose the family home that we have both worked hard for.²²⁶

2.135 Many contributors to the inquiry noted thalidomide survivors face high costs for healthcare, such as out-of-pocket costs for surgery, and high costs for disability supports such as home modifications.²²⁷ Additional costs to

²²² Andrew, *Committee Hansard*, 31 January 2019, p. 71.

²²³ See, for example, Name withheld, *Submission 10*, p. 4.

²²⁴ UK Thalidomide Trust, *Loss of earning and pensions among UK thalidomide survivors*, November 2016, p. 7.

²²⁵ Name withheld, *Submission 46*, p. 2; Name withheld, *Submission 21*, pp. 1–2.

²²⁶ Name withheld, *Submission 41*, [p. 3].

²²⁷ See, for example, Ms Newbronner, *Submission 63*, p. ; Name withheld, *Submission 30*, [p. 1]; Name withheld, *Submission 36*, [p. 3]; Name withheld, *Submission 37*, [pp. 1–2]; Name withheld, *Submission 40—Attachment 1*, [p. 1]; Name withheld, *Submission 54*, [pp. 1–2].

thalidomide survivors also arise from less obvious sources. For example, one survivor explained their increased energy costs:

Other 'unusual' electrical expenses include the need for underfloor heating with floorboard covering, as I naturally need to be bare-footed daily to compensate for the lack of arms. The heating is also necessary to assist with the peripheral nerve damage caused by Thalidomide. Without the heating I experience excruciating pain which includes the sensation of pins and needles, and feels like walking on glass every day. I also require cooling as soon as the weather gets warm to assist with a heart disorder which can also be attributed to Thalidomide. Another added expensive to the running of my household.²²⁸

2.136 Other contributors told the committee that thalidomide survivors faced increased energy costs as a result of heating and cooling their homes to assist in regulate their body temperatures.²²⁹ Costs can also arise from other unexpected sources, such as having to employ the services of a dress maker to alter clothes to fit the differing body of a thalidomide survivor.²³⁰

2.137 For some survivors, the compounding effects of reduced income and high costs appear to have left them financially vulnerable. Submissions describe survivors' anxiety regarding their future financial wellbeing, particularly regarding whether they can afford costs associated with increasing support requirements. For thalidomide survivors who may require early access to aged care, concerns have been raised as to whether survivors can meet this cost.²³¹ One survivor described their concern regarding their financial future:

...my biggest fear is not having the finances to pay for all the assistance about the home, any needed future medical treatment or possible modifications to my car or home.²³²

2.138 The committee received evidence that some thalidomide survivors and their family members may also have low superannuation savings.²³³

2.139 Chapter 4 of this report considers the adequacy of the financial support and compensation currently received by Australia's thalidomide survivors.

²²⁸ Name withheld, *Submission 42*, [p. 4].

²²⁹ Miss Michaelina Argy, Deputy Chair, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, pp. 12–13; Name withheld, *Submission 11*, p. 4.

²³⁰ Name withheld, *Submission 42*, [p. 4].

²³¹ See, for example, Name withheld, *Submission 10*, p. 5; Thalidomide Group Australia, answers to questions on notice, 2 November 2018 (received 20 November 2018).

²³² Name withheld, *Submission 50*, [p. 4].

²³³ See, for example, Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 5; Mark, *Committee Hansard*, 31 January 2019, p. 27; Name withheld, *Submission 14*, p. 2; Name withheld, *Submission 18*, [p. 3]; Name withheld, *Submission 21*, [p. 2]; Name withheld, *Submission 40*, [p. 2].

Committee view

- 2.140 The evidence provided to this inquiry has made clear that every aspect of the lives of most thalidomide survivors, has been adversely impacted by thalidomide. In hearing evidence from thalidomide survivors regarding the challenges they have faced throughout their lives, the committee particularly noted the difficulty of survivors' circumstances, and the resilience survivors and their families demonstrated in seeking to live life on their own terms.
- 2.141 The committee considers the evidence provided during the inquiry shows thalidomide survivors' injuries often made it difficult for survivors and their families to live on a day to day basis, to access education, to participate in the workforce, and to establish their financial security. The committee is concerned that following a lifetime of disadvantage, some thalidomide survivors may not have adequate resources to support themselves in the future, particularly as their impairments and health conditions worsen. The committee recognises that the uncertainty regarding their future has caused many thalidomide survivors, and their families, anxiety and concern.

Chapter 3

Supports required to live with dignity

Those fine threads of independence that were ours, are quickly slipping away. Daily, our needs increase. Daily, we rely more and more on the support of others. And daily, we move closer to requiring full-time care.¹

- 3.1 Thalidomide survivors have been largely self-sufficient for more than 50 years.² Thalidomide survivors have worked (where possible), invested and supported themselves with limited assistance from the Australian or state and territory governments. This means that the financial burden associated with medical treatment, assistive equipment and home and vehicle modification has largely been incurred by thalidomide survivors and their families.³ However, as noted in Chapter 1, support from the distributor may have assisted with some costs.
- 3.2 The previous chapter explained the impacts that injuries caused by thalidomide pose for thalidomide survivors and their families. It noted that in addition to the congenital malformations caused by thalidomide, thalidomide survivors are experiencing premature aging and their bodies are deteriorating at a faster rate than the broader population because:
- survivors have been required to use their bodies to maintain their independence in ways other people have not;
 - some of the internal injuries caused by thalidomide may only be presenting with early onset ageing; and
 - some thalidomide survivors are experiencing nerve neuropathy.⁴
- 3.3 This chapter explores what thalidomide survivors need to maintain their independence and quality of life for the longest period of time possible and considers whether the supports that are currently available to them will be adequate to support them if they require additional assistance.
- 3.4 As noted in Chapter 2, survivors' circumstances vary widely. Thalidomide survivors who contributed to the inquiry detailed a wide array of injuries that have affected their lives, revealing that a broad spectrum of needs should be considered in determining how best to support thalidomide survivors into the future.

¹ Thalidomide Group Australia, answers to question on notice, 2 November 2018, p. 6 (received 20 November 2018).

² Thalidomide Group Australia, *Submission 1*, p. 3.

³ See, for example: Name withheld, *Submission 11*, pp. 3–4; Name withheld, *Submission 42*, [p. 4].

⁴ See Dr Debra Kennedy, *Committee Hansard*, 31 January 2019, p. 5; Ms Elizabeth Newbronner, *Submission 63*, pp. 2–3.

Health requirements

3.5 As noted in Chapter 2, many thalidomide survivors are concerned about their financial futures and their ability to meet their increasing medical needs as they age.⁵ If thalidomide survivors are to maintain their independence and have the highest possible quality of life for as long as possible, they are likely to need considerable health supports and assistance in paying for those services.

Surgeries

3.6 In Chapter 2, it was noted that thalidomide survivors have already undergone significant surgeries to improve their quality of life. In some cases, such as in the case of women who have had mastectomies, thalidomide survivors have felt compelled to have significant surgery in order to maintain their independence and ensure that their conditions were not exacerbated.⁶

3.7 Survivors and their families reported that they have needed to pay for these procedures out of their own pockets and have not been specially assisted or subsidised.⁷ Survivors told the committee that these costs varied from modest amounts to approximately \$40 000 for a major back operation.⁸

3.8 Thalidomide survivors are currently experiencing the effects of premature ageing because of the effects of thalidomide. Survivors advised the committee that they have been told by medical professionals that they are almost certain to require further surgery and medical intervention because of these effects including:

- open heart surgery and other surgeries to try and repair the damage thalidomide has caused to internal organs;⁹
- shoulder reconstructions;¹⁰ hip replacements;¹¹ arthroscopies and knee replacements¹² as a result of needing to contort their bodies to carry out routine tasks and strive to maintain their independence;
- mastectomies to reduce pressure on a survivor's back and neck and prevent injuries;¹³

⁵ See, for example: Name withheld, *Submission 6*, p. 5.

⁶ See paragraph 2.43.

⁷ Name withheld, *Submission 11*, p. 4; Name withheld, *Submission 27*, [p. 1].

⁸ Name withheld, *Submission 17*, [p. 1]; See also: Name withheld, *Submission 48*, [p. 1].

⁹ Name withheld, *Submission 42*, [p. 3].

¹⁰ Barbara-Ann, *Committee Hansard*, 2 November 2018, p. 14; Name withheld, *Submission 23*, [p. 4].

¹¹ Name withheld, *Submission 27*, [p. 1]; Suanne, *Committee Hansard*, 31 January 2019, p. 48.

¹² Nola, *Committee Hansard*, 2 November 2018, p. 20; Name withheld, *Submission 27*, [p. 1].

¹³ Ms Lisa McManus, Director, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 6.

- ear and eye surgeries to manage the effects of their thalidomide injuries;¹⁴ and
 - dental surgery as a result of using their teeth to perform tasks such as dressing, opening jars, carrying shopping and turning keys in locks.¹⁵
- 3.9 As noted in Chapter 2, thalidomide survivors and their families consider that they are entering a period of financial vulnerability. Thalidomide survivors and their families have not been able to save or accumulate sufficient superannuation either because the effects of thalidomide have reduced their capacity to work or because their injuries have required their spouse or family members to take time out of their own careers to become carers.¹⁶ As a result, some thalidomide survivors are concerned that they will not be able to afford to have the surgery or access the supports that they need based on their existing resources.¹⁷
- 3.10 Survivors are concerned that, other than the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme, there is no government assistance to reduce the cost of medical procedures. The National Disability Insurance Scheme (NDIS), for example, does not pay for medical expenses, even if they are related to or are necessary to treat a survivor's disability.¹⁸

Physiotherapy, massage, chiropractic

- 3.11 Thalidomide survivors advised the committee that many of them live with chronic pain because of the way their injuries have required them to manipulate their bodies to compensate for the absence of limbs or the absence of strength in affected limbs.¹⁹ To deal with this pain and to maintain the functionality that they have, survivors often require regular support from a physiotherapist,²⁰ massage therapist²¹ or chiropractor.²²
- 3.12 Some thalidomide survivors told the committee that therapy is essential to enable their continuing mobility.²³ The following comment from the spouse of

¹⁴ Vicki, *Committee Hansard*, 31 January 2019, p. 16; Name withheld, *Submission 36*, [p. 2]; Name withheld, *Submission 40*, [p. 2]; Name withheld, *Submission 43*, [p. 1].

¹⁵ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 6.

¹⁶ See paragraphs 2.114; 2.119–2.123.

¹⁷ Name withheld, *Submission 42*, [p. 3].

¹⁸ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 6.

¹⁹ Name withheld, *Submission 43*, [p. 2].

²⁰ Name withheld, *Submission 42*, [p. 3].

²¹ Name withheld, *Submission 37*, [p. 1].

²² Name withheld, *Submission 9*, [p. 1]; Name withheld, *Submission 17*, [p. 1]; Name withheld, *Submission 37*, [p. 1].

²³ Name withheld, *Submission 28*, [p. 1]; Name withheld, *Submission 43*, [pp. 1–2].

a thalidomide survivor is representative of comments the committee received about the necessity of these forms of therapy to manage pain and to sustain mobility:

...without the physio [my wife] would lose her mobility and quality of life and her pain levels would possibly become unbearable.²⁴

3.13 Other thalidomide survivors told the committee that physiotherapy, chiropractic services and body massages form part of a broader regime designed to manage their pain and assist with maintaining mobility:

With my chronic pain throughout my body I have to have regular Chiropractic sessions, Osteopathy, massage & dry needling, plus a cocktail of painkillers.²⁵

Cost of physiotherapy, massage and chiropractic services

3.14 While these supports are vital for thalidomide survivors, they can also be very expensive to access on a regular basis.²⁶ The committee received evidence that some thalidomide survivors require these services as often as once or twice a week and this could cost survivors 'a couple of hundred dollars per week'.²⁷

3.15 Some survivors and their families have submitted that they consider that their financial situation is too precarious for them to afford physical therapy, even though they may be in constant pain. The committee received one submission from a thalidomide survivor who advised that family members were providing massages in lieu of professional assistance to try and alleviate pain because he did not consider that he was financially able to obtain those services.²⁸

3.16 Thalidomide survivors and their families who provided evidence to the committee advised that survivors would use physiotherapy, chiropractic and massage therapy services, or use them more regularly, if the funds were available.²⁹

Supports currently available

3.17 The Department of Health advised the committee that thalidomide survivors may be able to access allied health services in one of three ways:

- through public-sector allied health services provided by state and territory government programs;

²⁴ Name withheld, *Submission 21*, p. 4.

²⁵ Name withheld, *Submission 9*, [p. 1].

²⁶ Name withheld, *Submission 37*, [p. 1].

²⁷ Name withheld, *Submission 21*, p. 3; Name withheld, *Submission 42*, [p. 3].

²⁸ Name withheld, *Submission 40—Attachment 1*, [p. 1].

²⁹ Name withheld, *Submission 46*, [p. 3].

- through private allied health services that may be included as part of a private health insurance policy held by the survivor; or
 - the survivor may be eligible for services under the MBS Chronic Disease Management items.³⁰
- 3.18 The Department of Health explained that Chronic Disease Management items are available to people with chronic health conditions after consultation with a General Practitioner (GP) to develop a management plan.³¹ Once a management plan has been developed, the patient can be referred by their GP for up to five allied health services each calendar year that are considered to be directly related to management of the patient's chronic condition.³²
- 3.19 The committee was advised by the Department of Health that the eligible Chronic Disease Management allied health services include audiology, chiropractic, mental health work, occupational therapy, osteopathy, physiotherapy, podiatry and psychology. Massage therapy is currently not an eligible service.³³
- 3.20 The Thalidomide Group Australia advised the committee that as no comprehensive survey of the health of thalidomide survivors has been undertaken it was unable to say whether or how many members of Thalidomide Group Australia have a Chronic Disease Management Plan.³⁴

Health professionals' understanding of thalidomide injuries

- 3.21 Thalidomide survivors raised concerns that their thalidomide injuries are not well understood by the medical professions or in the wider community.³⁵ Given the complex nature of their conditions, it is vital that thalidomide survivors receive suitable medical care.³⁶ In some cases, health professionals have declined to treat survivors because they did not consider that they had the expertise to do so.³⁷

³⁰ Department of Health, answer to written question on notice, No. 13, [p. 18] (received 27 November 2018).

³¹ Department of Health, answer to written question on notice, No. 13, [p. 18] (received 27 November 2018).

³² Department of Health, answer to written question on notice, No. 13, [p. 18] (received 27 November 2018).

³³ Department of Health, answer to written question on notice, No. 13, [p. 18] (received 27 November 2018).

³⁴ Thalidomide Group Australia, answer to written questions on notice, No. 5, p. 7 (received 24 January 2019).

³⁵ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

³⁶ Dr Debra Kennedy, *Committee Hansard*, 31 January 2019, p. 2.

³⁷ Name withheld, *Submission 21*, p. 3.

Lack of knowledge in the medical community about thalidomide

- 3.22 As noted above, thalidomide survivors require, and are likely to continue to require, treatment by a multi-disciplinary team of health professionals who understand the nature of thalidomide injuries and the best way to treat them.³⁸
- 3.23 Throughout the inquiry the committee tried to find medical and allied health practitioners in Australia who might be able to assist it to understand the challenges thalidomide survivors faced from a practitioner's perspective. In a number of cases, professional organisations advised the committee that none or almost none of their members had sufficient experience in treating thalidomide survivors.³⁹
- 3.24 Clinicians told the committee that most specialists, such as orthopaedic surgeons, do not have the relevant expertise to understand the effect that thalidomide may have had to be able to properly diagnose and treat thalidomide survivors' injuries.⁴⁰ Thalidomide survivors told the committee that, in some cases, this paucity of knowledge extended to even the most basic understanding of thalidomide:
- In 2010, many doctors were now asking me, 'What is wrong with you?' I would say, 'Thalidomide,' and they would say, 'What is that?'⁴¹
- 3.25 Thalidomide survivors told the committee that a lack of knowledge among health professionals about thalidomide was common, meaning that survivors felt that they had to educate medical and health practitioners about thalidomide:
- I've lived in several states over the years and still have had no luck in finding a GP or a medical specialist who has been educated about thalidomide. I'm always having to educate them.⁴²
- 3.26 The committee was informed that this education could even include basic medical tasks such as measuring blood pressure or drawing blood if thalidomide survivors had malformed limbs.⁴³
- 3.27 In terms of promoting awareness about thalidomide injuries and their impacts, the Department of Health advised the committee that it is the role of the Royal Australian College of General Practitioners (RACGP) and the Australian

³⁸ Dr Debra Kennedy, *Committee Hansard*, 31 January 2019, p. 2.

³⁹ See, for example: Australian College of Rural and Remote Medicine, answers to written questions on notice, [p.1] (received 25 January 2019).

⁴⁰ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, pp. 4–5; Name withheld, *Submission 42*, [p. 6].

⁴¹ Patricia, *Committee Hansard*, 31 January 2019, p. 21.

⁴² Fiona, *Committee Hansard*, 31 January 2019, p. 25.

⁴³ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 4; Name withheld, *Submission 42*, [p. 6].

College of Rural and Remote Medicine (ACRRM) to provide professional guidance to the medical profession.⁴⁴

- 3.28 The ACRRM advised the committee that while none of its members had been called on to treat a thalidomide survivor, it was willing 'to play a useful role in raising awareness and disseminating information within our membership'.⁴⁵ The RACGP advised the committee that due to the small number of thalidomide survivors in Australia 'the majority of GPs will never have a consultation with a patient requiring ongoing management of thalidomide consequences'.⁴⁶ As a result, to ensure that GPs remain within their clinical scope of practice the RACGP suggested:

The most helpful course of action with this small number of survivors is for the GP to refer to a clearly identified assessment service so survivors receive a consistent evidence based assessment.⁴⁷

- 3.29 Part of the problem with the approach suggested by the RACGP is that no such service currently exists in Australia.
- 3.30 Ms Elizabeth Newbronner, a research fellow at the University of York, told the committee that in the United Kingdom the Thalidomide Trust had worked to identify a network of specialists who had an interest in and understanding of thalidomide injuries.⁴⁸ Ms Newbronner suggested that identifying a select network of practitioners who have an interest in thalidomide injuries may be more beneficial to survivors than attempting to promote a widespread understanding of thalidomide.⁴⁹
- 3.31 If that network of practitioners could be identified, in the absence of Australian expertise, international linkages might be able to be made to harness international expertise.⁵⁰ The committee has been advised that there are multi-disciplinary clinics in Hamburg, Germany, in Nijmegen, Netherlands and in Stockholm, Sweden that assist thalidomide survivors.⁵¹

⁴⁴ Department of Health, answer to written questions on notice, No. 14, [p. 19] (received 20 November 2018).

⁴⁵ Australian College of Rural and Remote Medicine, answers to written questions of notice, [p. 1] (received 8 January 2019).

⁴⁶ Royal Australian College of General Practitioners (RACGP), answers to written questions on notice, [p. 2] (received 1 February 2019).

⁴⁷ RACGP, answers to written questions on notice, received 1 February 2019.

⁴⁸ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 4.

⁴⁹ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, pp. 4–5.

⁵⁰ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 5.

⁵¹ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 6; NESOS Board of Dutch Thalidomide Survivors, *Submission 31*, [p. 1]; Professor Janet McCredie, *Submission 67*, p. 4.

3.32 Mr Lance Fletcher, Founder and President of Thalidomide Australia Incorporated, told the committee that survivor groups and others, especially in Germany and the United Kingdom, have expressed an interest in providing support to Australian thalidomide survivors and their health practitioners. Mr Fletcher noted that sharing knowledge would require some type of portal or infrastructure through which that knowledge could be shared:

They have been very generous in offering us their research outcomes, their medical knowledge and support; but we need to set up some way to tap into their information...we need a portal. We need a secure access point where we can get this information to our doctors so that they can treat us appropriately.⁵²

Committee view

3.33 The committee understands that survivors are in need of medical and allied health support to help maintain what mobility and independence they are able to retain for as long as possible. The committee understands that this can be quite expensive and while some support is available, the existing support does not appear to be sufficient to meet the existing or future needs of thalidomide survivors.

3.34 The committee is concerned that medical practitioners may not fully understand the effects of thalidomide injuries and why thalidomide survivors may need particular treatment. The committee considers that further work needs to be done to ensure that medical practitioners are better informed about the nature of thalidomide injuries. The committee notes evidence pointing to the need to identify practitioners in Australia who have expertise in treating thalidomide survivors and work with international clinics to make best-practice treatments available to thalidomide survivors in Australia. The committee considers that responsibility for this work should not be outsourced to survivors, but should be properly resourced by an appropriate body.

Aids to leading an independent life

3.35 While health supports are essential to maintaining mobility and relieving pain, aids and modifications can help to provide thalidomide survivors with the greatest degree of independence possible. In many cases, thalidomide survivors have already incurred the expenditure that is necessary to give them the independence and dignity they currently enjoy.

3.36 However, as thalidomide survivors age, they are likely to require additional assistance and need to either move homes or make further modifications to their homes to maintain a similar level of independence.⁵³

⁵² Mr Lance Fletcher, Founder and President, *Committee Hansard*, 31 January 2019, p. 41.

⁵³ See, for example Ken, *Committee Hansard*, 31 January 2019, p. 50.

3.37 This is consistent with evidence the committee received from the UK Thalidomiders Campaign Team who advised that nearly 30 per cent of British thalidomide survivors expect to make further modification to their homes and 40 per cent of British thalidomide survivors have indicated that they expect to need to move house (for example to a house without stairs) as their health declines.⁵⁴

Home modifications

3.38 Thalidomide survivors told the committee that the nature of their injuries required their homes to be specifically configured to accommodate their needs. These modifications have placed a significant financial burden on thalidomide survivors and their families. In most cases thalidomide survivors needed to purchase their own homes in order to make the necessary modifications. As one thalidomide survivor told the committee:

Renting was never an option for me, as I required too many specific home modifications – beyond what a landlord would ever agree upon. Establishing a home catering to my specific needs was a very expensive exercise – costs of which [I] bore myself. Kitchen, bathroom and bedroom renovations specifically – have had to be very carefully designed to cater for my needs.⁵⁵

3.39 The range of modifications required includes benches to be a significantly different height, cupboard doors to have handles at the bottom to allow thalidomide survivors to open cupboards with their feet and modifications to facilitate access in a wheelchair.⁵⁶

3.40 To add to the challenge of modifying their homes, thalidomide survivors advised that they have found it difficult to find people who understand what needs to be done to cater for their injuries:

Home assist were sent out by the government and they offered to destroy our home both in terms of resale and practicality, and when they were finished [my wife] was still not going to be able to access the bathroom in a wheelchair. Best of all, we would have to pay for the work to be completed.⁵⁷

3.41 The committee received evidence that these modifications can be extremely costly. To provide an indication of cost, one Australian thalidomide survivor told the committee that their kitchen modification cost approximately \$40 000,

⁵⁴ UK Thalidomiders Campaign Team, *Submission 4*, [p. 3].

⁵⁵ Name withheld, *Submission 11.1*, [p. 1].

⁵⁶ Name withheld, *Submission 21*, p. 3; Name withheld, *Submission 37*, [p. 1]; Name withheld, *Submission 42 – Attachment 2*, [p. 1].

⁵⁷ Name withheld, *Submission 21*, p. 3.

and other modifications (such as modifying external doors) cost another \$20 000.⁵⁸

3.42 This is consistent with the evidence provided by a German survivor who advised the committee that a specialised kitchen that allowed them to reach the benchtops with their feet cost €20 000, a special toilet €5000 and a special wardrobe that they could access without their arms cost an additional €8000.⁵⁹ A survivor from the United Kingdom advised that an appropriate kitchen cost £40 000, an electrically adjustable bed cost £3250 and solar powered windows and blinds cost £3800.⁶⁰

3.43 Thalidomide survivors and their friends and family noted that not only did the physical structure of the house need to be adjusted, but many of the objects within the home need to be purchased to suit the thalidomide survivor's needs. The friend of one survivor told the committee:

Every part of her home is specifically chosen or adapted to increase her level of independence – the furniture, cutlery, crockery, kitchen appliances, television, washing machine, dishwasher, household items, computer system, door locks, gate latch, handbag – the list is long and extensive.⁶¹

3.44 These are all supports that thalidomide survivors and their families have had to fund to enable a degree of independence. To date, there has been little, if any, support to assist thalidomide survivors to modify their homes.

3.45 However, as thalidomide survivors age, many have indicated that, if they had the financial means to do so, they would make additional modifications to their homes to allow them to manage and remain in their homes.⁶²

3.46 Ms Elizabeth Newbronner explained that her research in the United Kingdom found that as thalidomide survivors age, their needs evolve meaning that aids or modifications that may have been appropriate a number of years ago may no longer be adequate. This means that even if thalidomide survivors may have previously received payments, these are not necessarily adequate to meet thalidomide survivors' needs going forward:

[Thalidomide survivors'] needs are continuing to evolve, and so their homes, cars and equipment also continue to need to be evolved. They're not one-off costs.⁶³

⁵⁸ Name withheld, *Submission 42*, [p. 4].

⁵⁹ Name withheld, *Submission 30*, [p. 1].

⁶⁰ Name withheld, *Submission 29*, [p. 1].

⁶¹ Name withheld, *Submission 42—Attachment 1*, [p. 1].

⁶² Rick, *Committee Hansard*, 2 November 2018, p. 15; Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 20*, [p. 2]; Name withheld, *Submission 21*, p. 1; Name withheld, *Submission 41*, [p. 3]; Name withheld, *Submission 42*, [p. 3].

⁶³ Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 6.

Vehicle modifications and mobility aids

3.47 Thalidomide survivors explained that having a vehicle provides mobility and independence.⁶⁴ However, having a vehicle modified is very expensive and can take a long time, potentially making it unaffordable for some people.

Cost of vehicle modifications

3.48 One survivor explained that in her experience getting a vehicle modified can take a number of years:

With the amount of modifications required to ensure driving was a safe activity for me, it was unrealistic to purchase anything other than a new vehicle on the two (2) occasions I have done so. My first vehicle took four (4) years and my second, 18 months – to modify. I had no financial assistance whatsoever in meeting the modification costs of either vehicle. The modification costs of my second vehicle equalled the amount of the vehicle itself!⁶⁵

3.49 This is consistent with international evidence received by the committee that suggested that having a vehicle modified with foot steering cost one German thalidomide survivor €24 000.⁶⁶ Ms Newbronner advised the committee that in some cases car modifications could cost up to £60 000.⁶⁷

3.50 Until the establishment of the NDIS, survivors have had to self-fund vehicle modifications and mobility equipment because no government subsidy scheme has existed. One submitter told the committee that she both needed to purchase the mobility scooter and pay to have someone modify it for her because no government funding was available to assist her.⁶⁸

3.51 Thalidomide survivors who use an electric wheelchair advised the committee that they need to purchase two wheelchairs to ensure that they are able to move at all times while the batteries were being charged on the other wheelchair at night.⁶⁹

Disabled parking permits

3.52 Thalidomide survivors and their partners reported that survivors have experienced difficulty in obtaining disabled parking permits at different times in their lives.⁷⁰

⁶⁴ Name withheld, *Submission 47*, [p. 1]. See also Grünenthal GmbH, *Submission 65*, [p. 6].

⁶⁵ Name withheld, *Submission 11*, p. 4 (emphasis removed).

⁶⁶ Name withheld, *Submission 30*, [p. 1].

⁶⁷ Ms Newbronner, *Committee Hansard*, 31 January 2019, p. 6.

⁶⁸ Name withheld, *Submission 14*, p. 3.

⁶⁹ Ms Michaelina Argy, Deputy Chair, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 9; Name withheld, *Submission 14*, p. 3.

⁷⁰ Name withheld, *Submission 10*, p. 3.

- 3.53 The wife of a survivor recounted her husband's recent experience applying for a disabled parking sticker:

In recent years [her husband] has applied to get a disabled parking sticker, as his arms are getting so much weaker, and it is very difficult for him to carry items which are quite light for a normal bodied person, but extremely heavy for [him]. He was denied this permit, basically, because NOTHING was wrong with his legs, and he could walk the distance.⁷¹

- 3.54 Other thalidomide survivors have experienced similar difficulties in obtaining disability parking permits.⁷² This included survivors who had significant physical disabilities. When they were denied their respective permits, thalidomide survivors adopted different approaches. Some survivors continued to park in disabled carpark without the permit rather than try to carry parcels and shopping bags over greater distances. In other cases survivors managed the burden, despite the additional strain that it placed on their bodies.⁷³

- 3.55 Even if thalidomide survivors were successful in obtaining a disabled parking permit, the committee was told that individuals need to go back to a doctor for an annual confirmation that the parking permit is required. One thalidomide survivor issued a warning to others:

Other thalidomide people should be aware that it's a minefield to get a disabled parking [permit]. And then they want you to go in every year. My arms aren't going to grow back!⁷⁴

National Disability Insurance Scheme

- 3.56 The NDIS provides support to Australians under the age of 65 with a permanent and significant disability.⁷⁵ The NDIS only funds supports that are 'most appropriately funded under the NDIS and are not more appropriately funded or provided through other general systems of service delivery or support services, such as the health system'.⁷⁶

- 3.57 Some thalidomide survivors noted that the NDIS is not yet available in all areas, but those who have had experience with it expressed concern that it will not be adequate to support them, either now or as they age.⁷⁷

⁷¹ Name withheld, *Submission 46*, [p. 3].

⁷² Greg, *Committee Hansard*, 31 January 2019, p. 47; Name withheld, *Submission 10*, p. 3.

⁷³ See, for example: Greg, *Committee Hansard*, 31 January 2019, p. 47; Name withheld, *Submission 10*, p. 3.

⁷⁴ Greg, *Committee Hansard*, 31 January 2019, p. 48.

⁷⁵ Department of Health, *Submission 2*, p. 4; Department of Social Services, *Submission 3*, [p. 3].

⁷⁶ Department of Social Services, *Submission 3*, [p. 3].

⁷⁷ Name withheld, *Submission 14*, p. 3.

3.58 Some thalidomide survivors are concerned because some of the people they know have not necessarily felt better supported under the NDIS. One thalidomide survivor told the committee about her early perceptions of the NDIS:

NDIS looks terrific on paper, though, in real life, it doesn't work, apart from the few very lucky participants who are better off with it, many I know are worse off once they are under the NDIS. It is not in my area...But I've been told already that they won't modify my bathroom as I want or need it done, they won't buy me a new mobility scooter, it is doubtful whether they will give me all new doors so that I can have keyless entry into every door in my house, imagine putting the key in your mouth and placing the key in the lock then turning it with your mouth.⁷⁸

3.59 Some thalidomide survivors are worried that if additional support is not forthcoming, the NDIS will be the only support that is available to them. For some survivors that prospect is distressing because they do not consider that the scheme is adequate to address their needs. One survivor who has been prominent in advocating for additional support for thalidomide survivors told the committee that there appears to be a mismatch between what policymakers consider the NDIS can deliver and the reality faced by thalidomide survivors.⁷⁹

Access and support available under the NDIS

3.60 To become an NDIS participant, a person must make an access request. If the participant is eligible, they will then be assessed and a plan will be developed.⁸⁰ As noted above, one of the criteria for eligibility is that the person is under the age of 65. However, the NDIS will provide assistance to people over the age of 65 provided they joined the scheme before they turned 65 and they age in the scheme.⁸¹

Is the NDIS adequate to accommodate thalidomide survivors' needs?

3.61 Thalidomide survivors raised concerns about whether the NDIS was sufficiently flexible to meet their needs.⁸² If it is not sufficiently flexible, then the scheme may not be able to provide supports that are of an appropriate type or in a timely manner.

3.62 The National Disability Insurance Agency (NDIA) told the committee that when a new participant comes in for their access decision, if the participant has

⁷⁸ Name withheld, *Submission 14*, p. 3.

⁷⁹ Name withheld, *Submission 14*, p. 3.

⁸⁰ NDIS, *How the NDIS works*, <https://www.ndis.gov.au/understanding/how-ndis-works> (accessed 4 February 2019).

⁸¹ Ms Vicki Rundle, Deputy Chief Executive Officer, National Disability Insurance Agency (NDIA), *Committee Hansard*, 31 January 2019, p. 57.

⁸² Suanne, *Committee Hansard*, 31 January 2019, p. 49.

a diagnosis that is well recognised it can be easier to understand the effect of that disability and therefore identify what they may need in order to function well. The NDIA explained that it is easier in those cases to determine what a participant might need because there is a code associated with the disability that allows a planner to see what other participants with that disability may have needed previously.⁸³ The NDIA told the committee that it does not have a code that can assist planners to deal with thalidomide survivors:

We don't have a code for people who are thalidomide survivors, for the condition, in our system and, therefore, we don't count that group of people. It is most likely that, if you looked at our actuarial data, you would find most people in the scheme who are thalidomide survivors in a category such as 'other physical conditions', which is quite a large category.⁸⁴

- 3.63 Under the NDIS, if a participant's circumstances change, they need to undertake a plan review in order to increase any supports that may be in place.⁸⁵ Occupational therapists, Ms Michelle French and Ms Amanda Cullen, told the committee that the evolving nature of thalidomide injuries, where needs can change dramatically and in a short period of time, could not be accommodated by the NDIS model.⁸⁶
- 3.64 The NDIA advised the committee that in September 2018 it announced the establishment of a complex disabilities pathway. Under this pathway, the NDIA considered that thalidomide survivors should be able to obtain a sufficiently individualised plan to meet their needs.⁸⁷

Are survivors' NDIS supports being reduced because of previous compensation?

- 3.65 The committee received conflicting reports from thalidomide survivors about whether the ex gratia payments that they received from the Thalidomide Australia Fixed Trust or the class action had been taken into account by the NDIA in developing their plan. Whether the sums were taken into account may have affected how much support the thalidomide survivor was eligible for.
- 3.66 Some thalidomide survivors told the committee that the NDIA asked during their planning meeting about any compensation that they may have received. In some cases, thalidomide survivors disclosed that they had received modest

⁸³ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 56.

⁸⁴ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 56.

⁸⁵ Ms Chris Faulkner, General Manager Advisory Services, NDIA, *Committee Hansard*, 31 January 2019, p. 57.

⁸⁶ Ms Michelle French, Director, Michelle French + Associates, *Committee Hansard*, 31 January 2019, p. 36.

⁸⁷ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 63.

compensation and an ex gratia sum.⁸⁸ In other cases, thalidomide survivors told the committee that they did not consider that they were able to disclose the amount that they had received because of the confidentiality agreement they signed as part of the agreement to provide the ex gratia payments and had informed the agency accordingly.⁸⁹

3.67 The NDIA told the committee that it was routine practice for planners to ask about compensation payments because the agency is required to consider whether a person should be required to take action to try and obtain compensation under the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act).⁹⁰

3.68 The NDIA observed that the NDIS Act contains a power for the Chief Executive Officer of the agency to disregard certain payments 'if the CEO thinks it is appropriate to do so in the special circumstances of the case'.⁹¹

3.69 However, the Deputy Chief Executive Officer of the NDIA told the committee that it had received advice that it was not able to develop a standing exemption from the compensation considerations because of the way the NDIS Act is drafted:

It's not possible because of the way the act is constructed...We are required to ask that, just as we are required, unless there are reasons to exempt, to both recover costs and to consider future costs and future supports in the scheme against the compensation for future compensation. [sic] We're required to do that and there is no way, unless the act is rewritten that we can get around that.⁹²

3.70 The NDIA advised the committee that in order to develop a standing exemption for thalidomide survivors, there would need to be an amendment to the NDIS Act.⁹³

3.71 The NDIA advised the committee that in the interim, it may be able to develop fact sheets about thalidomide to assist planners to make consistent decisions and to ensure that the question about whether there are special circumstances is considered in each case.⁹⁴

⁸⁸ Andrew, *Committee Hansard*, 31 January 2019, p. 19.

⁸⁹ Mark, *Committee Hansard*, 31 January 2019, p. 25.

⁹⁰ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 55.

⁹¹ *National Disability Insurance Scheme Act 2013* (Cth), s. 116. See also Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 55.

⁹² Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 58.

⁹³ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 58.

⁹⁴ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 60.

Barriers to access experienced by thalidomide survivors

3.72 Thalidomide survivors raised concerns about some of the difficulties they had experienced when attempting to access the range of services that they had been offered by the NDIS. These included difficulties in accessing essential assistive technology and equipment to enable mobility.

Waiting times for essential services under the NDIS

3.73 The committee received a number of examples where supports that have been requested through the NDIS have taken an extensive period of time to arrive. Box 3.1 recounts the experience of a survivor who was trying to get a bidet replaced by the NDIS. The experience demonstrates that survivors have can wait up to 15 months for routine supports that are vital to their care.

Box 3.1 Case study – waiting times for essential services under the NDIS

I have been waiting 12 – 15 months to replace a Bidet... The bidet is an essential item for providing personal hygiene. All I wanted from the NDIS was to provide funding for a replacement. However the process required an initial evaluation by Occupational Therapists of my need for the bidet...It took several months for the OT report to be written and submitted and several months before a quote for supply and installation was provided to the [National Disability Insurance Agency]. As of this moment I have no idea where process is up to and all the while I must put up with a dirty bottom as I am unable to clean myself properly...if I had a lump sum funding I could simply purchase and have the bidet installed in a much shorter period of time.⁹⁵

3.74 The survivor explained to the committee that during the 15 or more months it took for the bidet to be replaced, the absence of that piece of equipment had a profound effect on his life:

I actually go to the toilet every day. I have to clean my bum once a day in the shower by using my feet. I have to kneel down on the ground—and I have arthritis in my knees—balance a face cloth on my heel and wipe my bum as best as I can.⁹⁶

3.75 The NDIA accepted that in the case described in Box 3.1 above, the agency had made a mistake and that it had taken a period of time for the agency to identify and correct that mistake.⁹⁷

3.76 More broadly, the NDIA accepted that many participants who requested items of assistive technology had similar experiences because its business practices had been overly cumbersome. The NDIA recognised that its poor set up for assistive technology had generated a significant number of plan reviews,

⁹⁵ Name withheld, *Submission 50*, [p. 5].

⁹⁶ Mark, *Committee Hansard*, 31 January 2019, p. 20.

⁹⁷ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 56.

noting that it was still working on clearing the backlog.⁹⁸ The NDIA advised the committee that it has subsequently amended its business practices to ensure that items up to \$1500 no longer required a quote and it was looking to increase that limit to ensure that only very expensive bespoke items require a quote.⁹⁹

Transport and the importance of listening to survivors

3.77 The NDIA advised the committee that reasonable and necessary supports that may be available to thalidomide survivors may include vehicle modifications and mobility and transfer equipment.¹⁰⁰ However, thalidomide survivors have experienced some difficulty in trying to procure vehicles and mobility aids from the NDIS. Box 3.2 recounts the experiences of a survivor who was trying to get a replacement mobility scooter through the NDIS. The experience demonstrates that it is important for local area coordinators and officers undertaking assessments to listen to thalidomide survivors when considering what supports they need.

Box 3.2 Case study – the importance of listening to thalidomide survivors

...when I got this funding in 2015 I asked if I could get a better scooter...They said they would send out an [occupational therapist]...she said I didn't need a scooter, I needed a wheelchair. I knew I didn't need an electric wheelchair (a) because it wouldn't fit in my car (b) because a wheelchair is tight fitting around the body as such, I wouldn't have been able to lift my leg or do anything for myself, such as get stuff out of my purse or just to use my mobile. This OT went ahead and ordered an electric wheelchair which cost the government \$25,000, nine months later...the wheelchair arrives and guess what? I couldn't use it and it wouldn't fit in the car...she didn't listen to me, she didn't understand my disability, hence the wheelchair was totally useless...I am the expert when it comes to what equipment or aides I need – what will and will not work for me, all because of my body and what thalidomide did to it.¹⁰¹

3.78 The families of some thalidomide survivors have expressed great frustration with the NDIS because they do not believe that survivors are being listened to. The husband of a thalidomide survivor told the committee that, even after his wife had appeared at the hearing, the NDIA officer maintained that his wife, who has a severe upper limb malformation, needed to demonstrate the limits

⁹⁸ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, p. 56.

⁹⁹ Ms Rundle, NDIA, *Committee Hansard*, 31 January 2019, pp. 56–57.

¹⁰⁰ National Disability Insurance Agency, answer to written questions on notice, SQ19-000003 [p. 3] (received 29 January 2019).

¹⁰¹ Name withheld, *Submission 14*, p. 3.

of her functional impairment rather than listen to her explanation of how her disability affects her.¹⁰²

- 3.79 Transport provides people with the freedom to move around in their community. Some survivors have never been able to drive, but in those cases, as noted in Chapter 2, their parents, spouses or other support people have often provided this assistance to the thalidomide survivor. In the case of thalidomide survivors who could drive, some of them have now surrendered their licences and their modified cars due to the stress that driving placed on their bodies.¹⁰³
- 3.80 In the absence of a vehicle, thalidomide survivors advised that public transport was not an adequate alternative. Thalidomide survivors noted that the lack of upper limbs or the lack of strength in their upper limbs can make catching buses dangerous. Thalidomide survivors and their family told the committee about some of the injuries that thalidomide survivors have sustained on public transport:
- [The thalidomide survivor] now relies on family, friends and mobility cabs for transport. Using public transport is not an option as without arms to provide balance she has previously fallen and broken her nose while using a bus.¹⁰⁴
- 3.81 For this reason, some thalidomide survivors, including some survivors who made confidential submissions, asked the committee to consider a Gold Card which would help to pay for taxis to enable them to reach their destinations safely.¹⁰⁵
- 3.82 The NDIA advised that where a person with a disability cannot use public transport, transport funding is available.¹⁰⁶

Committee view

- 3.83 The committee understands that living with disability can be very expensive because of the types of additional supports that a person needs to help them. The committee recognises that the modifications to homes and vehicles have come at a substantial cost to thalidomide survivors and their families because little government support or appropriate compensation has been available.

¹⁰² Name withheld, *Submission 21.1*, [p. 1].

¹⁰³ Name withheld, *Submission 20*, [p. 1]; Name withheld, *Submission 38*, [p. 2]; Name withheld, *Submission 42*, [p. 1]; Name withheld, *Submission 49*, [p. 1].

¹⁰⁴ Name withheld, *Submission 20*, [p. 1].

¹⁰⁵ See, for example: Nola, *Committee Hansard*, 2 November 2018, p. 21.

¹⁰⁶ National Disability Insurance Agency, answer to written questions on notice, SQ19-000003 [p. 3] (received 29 January 2019).

- 3.84 The committee recognises the concerns that thalidomide survivors hold about the NDIS. It is important that thalidomide survivors feel that the NDIS adequately meets their needs because if they do not, they are less likely to feel secure about their futures or to engage with the scheme. The committee considers that any payment from the trust or class action should not be considered by NDIA planners to reduce the amount of support otherwise available to thalidomide survivors. The committee notes that both the ex gratia payment and the class action settlement were provided to thalidomide survivors on the basis that the sums would be exempt for the taxation and social security income tests.¹⁰⁷ The committee considers that it is inconsistent if those sums are taken into account for the purposes of reducing NDIS supports, but not for other purposes. The committee understands that an amendment may be necessary to ensure consistent treatment.
- 3.85 The committee understands that thalidomide survivors have had frustrating experiences that have shaken their confidence in the system. The committee recognises that thalidomide survivors could procure goods and services more efficiently if they were provided with a lump sum or a substantial annual payment to help meet the substantial costs of their disability.
- 3.86 However, the committee notes that the NDIA says they are working to resolve those issues, including by developing a new complex disability pathway and streamlining business practices to promote obtaining assistive technology more efficiently.

Maintaining survivors' quality of life when greater assistance is required

- 3.87 While thalidomide survivors have set up their homes to enable them to have the greatest degree of independence possible, the committee heard that they are likely to need more support in and around the home as they age. As noted in Chapter 2, until now, survivors have largely managed with the support of their spouses, friends, family and colleagues.¹⁰⁸
- 3.88 Thalidomide survivors may be able to request assistance from the NDIS. One survivor advised the committee that he currently receives two hours per month for yard maintenance and six hours of domestic assistance each month through the NDIS.¹⁰⁹ Another survivor told the committee that she received 20 to 23 hours of home assistance per week through the NDIS, but this is clearly not enough:

I need help with showering, dressing, shopping, cooking, cleaning, walking and feeding my dogs and cats, driving to the doctor, physio,

¹⁰⁷ Department of Health, *Submission 2*, p. 3; Department of Social Services, *Submission 3*, [p. 1].

¹⁰⁸ See, for example: Name withheld, *Submission 21*, [pp. 1–2].

¹⁰⁹ Mark, *Committee Hansard*, 31 January 2019, p. 20.

hydrotherapy, going to the shops and everything else I've missed out on. Really, 23 hours is not enough.¹¹⁰

3.89 A number of thalidomide survivors advised the committee that they currently pay private providers to come in and provide home assistance.¹¹¹ Thalidomide survivors expressed concern that as they and their partners age, the range of services that they will need to pay for will increase. The concern for survivors is that they do not believe that they can continue to fund the services that they need without additional assistance.

Aged care – home care packages

3.90 Some support may be available to thalidomide survivors through the aged care system. Thalidomide survivors with complex needs may be eligible for a home care package.¹¹² A home care package is 'a coordinated package of care and services' to allow a person to live independently in their own home for as long as possible.¹¹³ Home care packages are available to people aged 65 and over who require services to allow them to stay in their homes.¹¹⁴ Home care packages are available to certain groups of people who are under the age of 65, including people who have a disability. If eligible, thalidomide survivors may be entitled to certain forms of assistance, including:

- personal services (such as bathing, toileting, dressing and undressing);
- meal preparation;
- mobility and dexterity (such as walkers, pressure relieving mattresses and mechanical devices for lifting);
- nursing and allied health services (such as occupational therapy or physiotherapy);
- transport and personal assistance (such as assistance with shopping, visiting health practitioners and attending social activities);
- aids and equipment directly associated with care needs; and
- assistive technology (such as devices that support mobility, communication and personal safety).¹¹⁵

3.91 There are four different levels of home care package to help meet different levels of care needs.¹¹⁶ However, there are costs associated with the delivery of

¹¹⁰ Suanne, *Committee Hansard*, 31 January 2019, p. 48.

¹¹¹ Joanne, *Committee Hansard*, 31 January 2019, p. 24; Ms Elizabeth Newbronner, *Committee Hansard*, 31 January 2019, p. 4.

¹¹² Myagedcare.gov.au, *About home care packages*, <https://www.myagedcare.gov.au/help-home/home-care-packages/about-home-care-packages> (accessed 21 January 2019).

¹¹³ Myagedcare.gov.au, *About home care packages* (accessed 21 January 2019).

¹¹⁴ Myagedcare.gov.au, *About home care packages* (accessed 21 January 2019).

¹¹⁵ Myagedcare.gov.au, *About home care packages* (accessed 21 January 2019).

¹¹⁶ Myagedcare.gov.au, *About home care packages* (accessed 21 January 2019).

home care packages. This includes the basic daily fee which is 17.5 per cent of the single person rate of the basic aged pension (currently \$10.43 per day or \$146.02 per fortnight) and an income-tested care fee depending upon the recipient's income.¹¹⁷

Aged care – residential aged care

3.92 If thalidomide survivors are no longer able to live independently, even with assistance, they may need to consider moving into residential aged care.¹¹⁸ Even though thalidomide survivors are only aged in their early to mid-50s, some have already contemplated entering full-time care.¹¹⁹ Thalidomide survivors recognise that there are two key considerations about entering aged care: how will they pay for residential aged care and whether the aged care facility will be able to cater to their needs?

3.93 As noted in Chapter 2, thalidomide survivors acknowledge that residential aged care is expensive and because of their precarious financial position, many survivors are anxious about how they are going to pay for it.¹²⁰ The Thalidomide Group Australia noted that 'years of reduced finances make it impossible to afford extended home care and, also limits the availability of quality aged residential care'.¹²¹

3.94 There are also concerns about whether residential aged care will be able to cater for a thalidomide survivor with high needs. One thalidomide survivor with high needs explained that generally the term 'accessible accommodation' in Australia evokes perceptions of ramps into buildings and railings in bathrooms. However, she noted that she and other thalidomide survivors cannot access many features of accessible bathrooms or accessible accommodation:

- I cannot even reach any Australia standardised rails – regardless of their purpose!
- I cannot reach toilet paper – even in an 'accessible' bathroom;
- I cannot reach into cupboards and drawers
- I cannot turn on taps without lengthened tap ware;
- I cannot open/close doors with rounded handles due to the limited digits (three (3)) on my one usable hand and,

¹¹⁷ Myagedcare.gov.au, *Research home care providers and work out the costs*, <https://www.myagedcare.gov.au/help-home/home-care-packages/research-home-care-providers-and-costs?fragment=costs> (accessed 21 January 2019).

¹¹⁸ Name withheld, *Submission 11*, p. 5; Name withheld, *Submission 11.1*, [p. 1].

¹¹⁹ Name withheld, *Submission 11.1*, [p. 1].

¹²⁰ Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 10*, p. 5; Name withheld, *Submission 11.1*, [p. 1]; Name withheld, *Submission 41*, [p. 5].

¹²¹ Thalidomide Group Australia, answers to questions on notice, 2 November 2018, p. 6 (received 20 November 2018).

- I cannot reach bed lighting switches even in 'accessible accommodation'.¹²²

3.95 This raised questions about who would be required to pay for such modifications if thalidomide survivors move to residential aged care before they turn 65 if it needs to be modified. The Department of Health notes that, where an NDIS participant who is under 65 years of age is in residential aged care place, the person may be eligible to receive some specialised equipment support related to their ongoing functional impairment through the NDIS.¹²³

3.96 The Department of Social Services noted at Senate Estimates that where modifications were required, the Department of Social Services would work with the Department of Health and the NDIA to ensure that NDIS participants received all of the reasonable and necessary supports available, even if this exceeded the \$78 000 Aged Care Funding Instrument.¹²⁴

Income supports

3.97 One form of assistance available to all Australians is income support. Depending upon a person's situation, a person may be entitled to one or more payments. Most relevantly for thalidomide survivors and their families, some support is available through the Disability Support Pension, Carer Allowance and Carer Payment. However, some thalidomide survivors have experienced difficulty accessing these payments.

Disability Support Pension

3.98 Some survivors informed the committee that they had experienced difficulty in accessing the Disability Support Pension, an income support payment that is designed to support people with 'permanent physical, intellectual and/or psychiatric impairments that prevent them from engaging in employment'.¹²⁵

3.99 To qualify for the payment, an individual must be assessed at '20 points or more under the Tables for the assessment of work-related impairment for Disability Support Pension' and be unable to participate in 15 hours or more of work per week for at least the next two years.¹²⁶

3.100 One survivor who has no arms and four conditions of the heart had her application for the Disability Support Pension denied on multiple occasions.

¹²² Name withheld, *Submission 11.1*, [p. 1] (emphasis removed).

¹²³ Department of Health, *Providers with younger people in residential aged care*, <https://agedcare.health.gov.au/programs/providers-with-younger-people-in-residential-aged-care> (accessed 21 January 2019).

¹²⁴ Ms Helen McDevitt, Group Manager, NDIS Transition Oversight, Department of Social Services, Senate Community Affairs Legislation Committee, *Committee Hansard*, 1 March 2018, p. 62.

¹²⁵ Department of Social Services, *Submission 3*, [p. 2].

¹²⁶ Department of Social Services, *Submission 3*, [p. 2].

According to the survivor, despite a face-to-face interview and signing paperwork with her feet, the officer failed to record her upper limb disability and instead only assessed the application on the basis of her heart condition.¹²⁷

3.101 Other thalidomide survivors have also reported difficulty obtaining a Disability Support Pension, despite some experiencing some substantial disabilities including under-developed arms and internal injuries,¹²⁸ cranial nerve damage and muscle pain,¹²⁹ and Mobius syndrome and hearing loss.¹³⁰

3.102 Some people have suggested that all thalidomide survivors should be made eligible for a Disability Support Pension or an Age Pension.¹³¹ Mr Fletcher from Thalidomide Australia Incorporated told the committee that in 2008 the then Parliamentary Secretary to the Minister for Health and Ageing endorsed the idea at a thalidomide survivors' conference:

The senator had a handwritten speech, but after seeing us, she put it aside and spoke from the heart, discussing what should be done by her government to support Australian thalidomide survivors. This included, in her words: 'Given the issues that you are all having and the acceleration of the ageing process, you all should be getting an age pension and a disability pension now'.¹³²

3.103 Thalidomide survivors noted that this did not come to fruition and that since then the eligibility criteria for the Disability Support Pension has been tightened significantly, making it harder for thalidomide survivors (and others) to become eligible to receive the additional support.¹³³

3.104 The Department of Social Services advised the committee that the Disability Support Pension is based on functional impairment and certain financial tests.¹³⁴ The Department of Social Services advised that a search of its electronic records did not indicate that any internal work had been done to see if thalidomide survivors could be deemed to be eligible for disability support payments.¹³⁵ However, the Department of Social Services noted that the

¹²⁷ Name withheld, *Submission 14*, p. 3.

¹²⁸ Name withheld, *Submission 18*, [pp. 1–2].

¹²⁹ Name withheld, *Submission 28*, [p. 1].

¹³⁰ Name withheld, *Submission 35*, p. 1.

¹³¹ Professor Janet McCredie, *Committee Hansard*, 31 January 2019, p. 3; Mr Peter Gordon, Senior Partner, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 35.

¹³² Mr Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 40.

¹³³ Nola, *Committee Hansard*, 2 November 2018, pp. 20–21; Mr Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 40.

¹³⁴ Mr Shane Bennett, Group Manager, Payments Policy Group, Department of Social Services, *Committee Hansard*, 2 November 2018, p. 37.

¹³⁵ Mr Bennett, Department of Social Services, answers to questions on notice, received 27 November 2018, [p. 1].

impacts of ageing are considered in the assessment process for the Disability Support Pension and that people who had previously applied were eligible to reapply with additional medical information.¹³⁶

Other forms of income support

3.105 The Department of Social Services noted in its submission that thalidomide survivors and their families may also be eligible for Newstart Allowance, Carer Payment and Carer Allowance and Commonwealth Rent Assistance.¹³⁷

3.106 Some thalidomide survivors informed the committee that they were currently in receipt of Newstart Allowance. However, they noted that it is difficult to fund disability supports on the funds provided.¹³⁸ Nola, a survivor who spoke to the committee in Melbourne, told the committee that she had lost a Bone Anchored Hearing Aid that she needs to help her communicate and feels unable to replace it on Newstart:

It was only last month that I accidentally lost my [Bone Anchored Hearing Aid]...I'm on Newstart, They've given me a healthcare card not a concession card. A concessions cards [sic] will cover it but a healthcare card won't, so now I'm up for \$6 ½ thousand for a brand new [Bone Anchored Hearing Aid]. Where am I going to get that kind of money from? Centrelink is not going to do anything. Medicare don't cover it. They cover other areas.¹³⁹

3.107 Another thalidomide survivor said she felt like she had 'fallen through the cracks in the system' when she was placed on Newstart because, despite being required to medically retire from a job she really enjoyed, she was not found to be eligible for the Disability Support Pension and had received very little compensation.¹⁴⁰

3.108 The committee did not receive any evidence to suggest that thalidomide survivors were in receipt of Commonwealth Rent Assistance.

Income support for family members

3.109 Despite the support or compensation that may have been provided to thalidomide survivors, no compensation has ever been provided to the parents or families of those survivors.¹⁴¹ Very little financial or emotional support or guidance was provided to the families of thalidomide survivors. Mr Peter

¹³⁶ Mr Bennett, Department of Social Services, answers to questions on notice, received 27 November 2018, [pp. 5–6].

¹³⁷ Department of Social Services, *Submission 3*, [p. 2–3].

¹³⁸ Name withheld, *Submission 28*, [p. 1]; Name withheld, *Submission 35*, p. 2.

¹³⁹ Nola, *Committee Hansard*, 2 November 2019, p. 20.

¹⁴⁰ Name withheld, *Submission 28*, [p. 1].

¹⁴¹ Patricia, *Committee Hansard*, 31 January 2019, p. 22; Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 33.

Gordon, a lawyer who represented many of the thalidomide survivors told the committee:

None of the carers have been compensated. There are mums and dads and families whose lives have been wrecked—severely affected for decades...there is a need for both financial compensation and...a deep need for reparations and justice.¹⁴²

- 3.110 The parents of thalidomide survivors have received very little financial assistance. In the 1970s, before thalidomide survivors reached the age of 25, parents were given the option of either reinvesting the interest that was accruing in the trust or taking the interest to help meet costs at home.¹⁴³ This led to a trade off because if parents elected to receive the interest, it reduced the amount that the thalidomide survivor ultimately received.¹⁴⁴
- 3.111 The family members of survivors advised that the only assistance they received was Carer Allowance. Whilst carers were appreciative, they noted that it did not adequately make up for what they were required to give up in order to become a full-time carer. One spouse told the committee that he calculated that the carers pension amounts to just \$2.42 per hour if you divide hours by the amount of the pension and the only consolation was knowing that his wife was receiving the best possible care.¹⁴⁵

Committee view

- 3.112 The committee understands that thalidomide survivors are concerned about the appropriateness of aged care and their ability to pay for it. The committee understands that much of this anxiety is part of an underlying concern about thalidomide survivors' financial futures and whether they will be able to purchase the services they need to be able to manage their condition and pain and live independently with dignity.
- 3.113 The committee recognises that there is some support available to assist thalidomide survivors when they require additional assistance. However, given the experiences thalidomide survivors have described when dealing with mainstream services, the committee is not confident that those services will be fit for purpose when survivors need them.
- 3.114 The committee recognises that some thalidomide survivors have experienced difficulty in accessing income support and recognises that being able to access either a Disability Support Pension and/or an Age Pension would make a substantial difference to some thalidomide survivors' lives. The question of

¹⁴² Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 33.

¹⁴³ Mrs Lesley Fletcher, Founder and Former Secretary, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, pp. 44–45.

¹⁴⁴ Mrs Fletcher, Thalidomide Australian Incorporated, *Committee Hansard*, 31 January 2019, p. 45.

¹⁴⁵ Name withheld, *Submission 21*, p. 2.

whether that would be sufficient to allow thalidomide survivors to live the rest of their lives independently with dignity is partly dependent upon whether the compensation that thalidomide survivors are receiving is adequate.

Chapter 4

Compensation and international government responses

...having money matters, not only because of what it can buy but how it makes people feel. Having money provides a sense of security...creates options and choices, particularly in relation to how best to maintain independence of preserve function.¹

- 4.1 Despite the differences in injury or need, survivors' evidence to the committee identified a common aspiration: to live the rest of their lives with dignity and in comfort.² The previous chapter demonstrated that thalidomide survivors will only be able to achieve that goal with a wide range of support and assistance. This chapter considers whether the compensation thalidomide survivors have received to date is sufficient to meet their needs now and in the future or whether additional financial support is required.

Requests from the Thalidomide Group Australia

- 4.2 The Thalidomide Group Australia has six requests for support it would like from the Australian Government.³
- 4.3 The requests from the Thalidomide Group Australia were:
- (a) a one-time upfront payment of up to \$500 000 for each thalidomide survivor to be scaled according to their degree of disability;
 - (b) an annual payment of \$2 190 260 to be exempt from income tax and social security income tests, to be distributed through the Thalidomide Australia Fixed Trust;
 - (c) a 'Gold Card' similar to the Department of Veterans' Affairs health card that provides access to a wide range of health services at the Commonwealth's expense;
 - (d) an 'Extraordinary Assistance Fund' of \$500 000 to allow survivors to adapt their homes, living environment and vehicles to accommodate their disabilities;
 - (e) a formal apology to Australian thalidomide survivors and their families; and

¹ Ms Elizabeth Newbronner, *Submission 63*, p. 5.

² See, for example: Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 14*, p. 2; Name withheld, *Submission 29*, [p. 1]; Name withheld, *Submission 41*, [p. 3]; Name withheld, *Submission 42*, [p. 6]; Name withheld, *Submission 47*, [p. 1].

³ Thalidomide Group Australia, *Submission 1*, p. 3.

(f) a plaque in recognition of Australian thalidomide survivors and their parents.⁴

4.4 The requests are based on similar supports that have been provided to thalidomide survivors by governments in other countries. Whether these requests are reasonable and necessary in the Australian context needs to be considered in light of the compensation that thalidomide survivors have received to date.

Compensation

Global context

4.5 As noted in Chapter 1, dangers of thalidomide were scientifically demonstrated in the early 1960s. However, thalidomide survivors were not compensated for another decade.

4.6 In 1968, the drug's manufacturer, Chemie Grünenthal, faced a criminal trial in Germany. The trial was suspended in December 1970.⁵ Earlier that year, Chemie Grünenthal had offered a settlement of DM100million, more than the company's total valuation in 1970, to support the survivors of thalidomide.⁶ However, Chemie Grünenthal only provided financial support where it had directly distributed the drug. In places where the drug had been distributed by a licensee—including the United Kingdom, Canada and Australia—Chemie Grünenthal did not contribute funds to support thalidomide survivors.⁷

4.7 Time has not changed Chemie Grünenthal's position. The company has continually resisted legal challenges for compensation both in Australia and overseas.⁸ Instead, the distributors of the drug have provided some compensation.

Compensation in Australia

4.8 Thalidomide survivors in Australia have not been uniformly compensated. Instead, thalidomide survivors who have been compensated by the Australian distributor of products that contained thalidomide, Distillers Company

⁴ Thalidomide Group Australia, *Submission 1*, p. 3.

⁵ The circumstances of the trial's conclusion remain contested. See, for example: Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 173; Harold Evans, 'Thalidomide: how men who blighted thousands of lives evaded justice', *The Guardian*, 15 November 2014, <https://www.theguardian.com/society/2014/nov/14/-sp-thalidomide-pill-how-evaded-justice> (accessed 11 January 2019).

⁶ State Claims Agency (Ireland), *Compensation for Thalidomide Survivors*, April 2010, pp. 3–4.

⁷ Grünenthal GmbH, *Submission 65*, [p. 4].

⁸ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 173; Harold Evans, 'Thalidomide: how men who blighted thousands of lives evaded justice', *The Guardian*, 15 November 2014.

Limited (Distillers), and its successor, Diageo Australia, fall into two broad categories: survivors who were first recognised in the 1970s as having been affected by thalidomide and a group who were identified in the 2010s.

Compensation for thalidomide survivors recognised in the 1970s

4.9 As noted in Chapter 1, in the early 1970s the Australian distributor of products containing thalidomide, Distillers, reached a settlement with the parents of children who were recognised as being affected by thalidomide.⁹ Part of the compensation package required the parents to waive their rights to recover additional compensation from Distillers at a later time, including by taking legal action.¹⁰

4.10 As part of the settlement, upon reaching 25 years of age, survivors received a 'modest' payment.¹¹ Until thalidomide survivors reached the age of 25, the payments from Distillers were held in trust, where they accrued interest.¹² These payments were provided on a sliding payment scale according to the survivor's level of disability.¹³

4.11 Mr Lance Fletcher, Founder and President of Thalidomide Australia Incorporated, advised the committee that the parents of thalidomide survivors were provided with a small amount of compensation to cover out-of-pocket costs that were directly related to the survivor's care:

In the 1970 process a lot of our parents had out-of-pocket expenses which they claimed and which Distillers paid. I think my mum and dad got about \$9,000 at that time. That was to cover the cost of me going to Melbourne for all my ear operations... There was a small payment to a lot of our parents, but they had to justify those costs to get that small payment.¹⁴

4.12 The committee received evidence that survivors' parents were provided with a choice about whether they would like to receive the interest payments that accrued from the trust. Survivors' parents had to decide whether they wanted to reinvest that interest in the trust or access it to meet their costs.¹⁵ If a survivor's parents could afford to reinvest the money, the survivor would

⁹ Ms Lisa McManus, Director, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 3; Department of Health, *Submission 2*, p. 3.

¹⁰ Department of Health, *Submission 2*, p. 3.

¹¹ Department of Health, *Submission 2*, p. 3.

¹² Mrs Lesley Fletcher, Founder and Former Secretary, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 44.

¹³ Department of Health, *Submission 2*, p. 3.

¹⁴ Mr Lance Fletcher, Founder and President, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 44.

¹⁵ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 44.

receive a larger sum when they reached the age of 25.¹⁶ However, if the survivor's parents needed to receive the interest payments to help meet their costs, the payment that the survivor received at 25 years of age would be substantially smaller. Mrs Lesley Fletcher, Founder and Former Secretary of Thalidomide Australia Incorporated told the committee that the payment her husband received had been 'small...compared to what it could have been had the interest been reinvested.'¹⁷

- 4.13 In 2010, Diageo Australia agreed to pay the same group of 36 recognised survivors an additional goodwill payment for a period of 18 years.¹⁸ These payments were procured after negotiations led by Mr Ken Youdale.

Assessments for the payments

- 4.14 Prior to receiving the goodwill payments, survivors were assessed to understand their level of disability. Ms Lesley Fletcher advised the committee that these assessments were undertaken by Professor Janet McCredie, Professor Earl Owen and Mr Peter Semmler QC over a three week period in 2010 at Diageo's expense.¹⁹

- 4.15 At the end of the assessments, thalidomide survivors were provided with a letter that advised them what category they were placed into, but they were not provided with copies of the assessments.²⁰

- 4.16 Mr Peter Gordon explained that thalidomide survivors may not have been provided with a copy of their records with a view to protecting their confidentiality. Reflecting on Mr Youdale's actions in coordinating the assessments, Mr Gordon told the committee:

...it was important to Ken [Youdale] to respect the integrity and the confidentiality of each of the 46 people who had given him a power of attorney. A lot of them know each other, and a lot of them want to keep much of their detail private. A lot of the people who were helping him in the process were beneficiaries themselves. So everything that was done, including the signing of confidentiality agreements, was done for a reason that made sense with the thalidomide community at that time...²¹

- 4.17 The committee understands that five copies of each survivor's assessment were made and that, while survivors do not have a copy, copies of all of the assessments may still exist.²²

¹⁶ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 44.

¹⁷ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, pp. 44–45.

¹⁸ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 5.

¹⁹ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

²⁰ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 43.

²¹ Mr Peter Gordon, Senior Partner, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 35.

²² Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 43.

Structure of the payments

- 4.18 Mr Peter Gordon, a lawyer who helped to negotiate the payments, told the committee that Diageo agreed in 2010 to pay thalidomide survivors \$35 million net present value.²³ Mr Gordon explained that this amount had been offered because it represented parity with the amount of money that had been provided by Diageo to thalidomide survivors in the United Kingdom.²⁴
- 4.19 These goodwill payments are provided to survivors through a trust, known as the Thalidomide Australia Fixed Trust. The trustees disperse the funds received from Diageo Australia to survivors on 1 April each year.²⁵ The payments are provided on a sliding scale according to the survivor's level of disability as assessed in 2010.²⁶ The Trustee of the Thalidomide Australia Fixed Trust and Ms Lisa McManus, Director of the Thalidomide Group Australia told the committee that there were five levels of payment.²⁷
- 4.20 Due to a confidentiality agreement, survivors were not able to inform the committee about the exact amount of money they were receiving from Diageo Australia, however, the committee understands that in 2018 the 36 survivors shared in \$2 190 260 and that this amount is not increased each year to account for inflation.²⁸ The Thalidomide Group Australia would like the Australian Government to match this amount.²⁹
- 4.21 Mr Gordon explained to the committee that the payments were front-loaded to ensure that thalidomide survivors shared in as much of the \$35 million ex gratia payment as possible. Mr Gordon advised that if approximately \$3 million is dispersed each year, then the goodwill or ex gratia payments will expire in 2028.³⁰ If one or more of the thalidomide survivors die before the payments expire, the amounts that would otherwise have been paid to them will be retained in the pool and dispersed to the remaining thalidomide survivors at the end of the period.³¹

²³ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 29.

²⁴ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 29.

²⁵ Mr Tim Kelly, Trustee, Thalidomide Australia Fixed Trust, *Committee Hansard*, 31 January 2019, p. 11.

²⁶ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 5.

²⁷ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 4; Mr Tim Kelly, Trustee, Thalidomide Australia Fixed Trust, *Committee Hansard*, 31 January 2019, p. 11.

²⁸ Lance, *Committee Hansard*, 31 January 2019, p. 17.

²⁹ Thalidomide Group Australia, *Submission 1*, p. 7.

³⁰ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 5.

³¹ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 29.

4.22 However, Mr Magazanik told the committee that these payments had not been matched to needs, but were calculated on a legal basis:

The 1970s, 2010, 2015—the payments then were never intended to match needs. Those were part of a legal process. It was all about what we could get, what would the defendant pay...One ought not look at the payments that are being made or that were made as having been intended to match need.³²

4.23 The Australian Government has ensured that these payments are tax exempt and are exempt from the social security income assets test.³³

Compensation provided to thalidomide survivors recognised in 2010s

4.24 In the 2010s, a class action against the manufacturer and the distributor of thalidomide was initiated on behalf of a group of 107 thalidomide survivors who had not previously been compensated.³⁴ The group was comprised of 95 Australian survivors and 12 survivors from New Zealand.³⁵ The survivors were represented in this action by a legal team led by Mr Peter Gordon, leading to this group of survivors sometimes being termed the 'Peter Gordon' group.³⁶

4.25 In 2014, the class action was settled by the distributor, Diageo Australia, for approximately \$89 million.³⁷ The amounts provided to each participating survivor was calculated according a complex formula that accounted for their level of disability and the strength of their legal case. This meant that the settlements varied from tens of thousands of dollars to multi-million dollar sums for survivors with the most severe injuries.³⁸

4.26 Despite the committee's endeavours to hear from them, thalidomide survivors from this cohort were not the major contributors to this inquiry.

Unrecognised survivors

4.27 The committee received some evidence that there may be Australian thalidomide survivors who have not yet been formally recognised and compensated.³⁹ The Department of Health advised the committee that it does

³² Mr Michael Magazanik, Partner, Rightside Legal, *Committee Hansard*, 31 January 2019, p. 35.

³³ Department of Health, *Submission 2*, p. 3; Department of Social Services, *Submission 3*, [p. 1].

³⁴ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 310.

³⁵ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 310.

³⁶ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, pp. 3–4.

³⁷ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 310.

³⁸ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 310.

³⁹ Ms Elizabeth Flynn, Assistant Secretary, Preventative Health Branch, Department of Health, *Committee Hansard*, 2 November 2018, pp. 30–31.

not know how many thalidomide survivors live in Australia.⁴⁰ The Department of Social Services also advised the committee that no analysis had been performed by the Department to ascertain how many thalidomide survivors lived in Australia.⁴¹

4.28 In her role as the Secretary of Thalidomide Australian Incorporated, Ms Lesley Fletcher advised the committee that even finding people who were known to be thalidomide survivors was difficult. Mrs Fletcher started trying to identify how many thalidomide survivors live in Australia in 2008. Between undertaking full-time work and being a parent it took Mrs Fletcher two years to try and identify the 40 Australian and nine New Zealand survivors who were known to Diageo.⁴²

4.29 One complicating factor in identifying how many thalidomide survivors are in Australia is that survivors may not be aware that thalidomide is responsible for their injuries. Mandy, a thalidomide survivor who spoke to the committee in Melbourne, explained that in some cases efforts had been made to disguise the cause of the child's injuries to try and save the mother from feeling guilty:

When I was born, actually, my father was a pathologist and he did a big cover-up that I wasn't thalidomide so that my mother wouldn't feel guilty about taking one tablet. So he...put my disability down to a virus. I went through the whole of my younger years, up until my early 30s, thinking my disability was from a virus. So I wasn't included in that first compensation.⁴³

4.30 The search for thalidomide survivors may also be complicated if medical science demonstrates that thalidomide can have an effect later than was previously thought. In Chapter 2, it was noted that there is a time-sensitive window within which thalidomide causes specific types of malformations, but Professor Neil Vargesson told the committee that, when thalidomide was applied outside the time-critical window, thalidomide could still result in mild damage to the embryo's internal organs.⁴⁴ Professor Vargesson explained that, in these cases, the damage caused to the internal organs could potentially remain undiagnosed until a person developed kidney or liver function problems in middle age, if it was diagnosed at all.⁴⁵

⁴⁰ Ms Flynn, Department of Health, *Committee Hansard*, 2 November 2018, p. 30.

⁴¹ Mr Shane Bennett, Group Manager, Payments Policy Group, Department of Social Services, *Committee Hansard*, 2 November 2018, p. 38.

⁴² Mrs Fletcher, Thalidomide Group Australia, *Committee Hansard*, 31 January 2019, p. 42.

⁴³ Mandy, *Committee Hansard*, 2 November 2018, p. 18.

⁴⁴ Professor Neil Vargesson, *Committee Hansard*, 31 January 2019, p. 5.

⁴⁵ Professor Neil Vargesson, *Committee Hansard*, 31 January 2019, p. 6.

4.31 Professors Janet McCredie and Neil Vargesson agreed that if this was the case then there could be many more unrecognised thalidomide survivors who did not know that their injuries had been caused by thalidomide.⁴⁶

Committee view

4.32 The committee recognises that there are two differently compensated groups of thalidomide survivors in Australia. Given their limited engagement in the inquiry, the committee is not in a position to assess the needs of thalidomide survivors who were party to the class action. However, the committee accepts that the originally recognised group of thalidomide survivors are in need of some additional financial support. As Mr Magazanik observed, the payments thalidomide survivors have been provided were determined based on legal factors and were never intended to match their needs. The committee considers that even though these thalidomide survivors have received some compensation, it does not appear to be adequate to meet their needs either now or into the future.

4.33 The committee recognises that there is a third group of Australian thalidomide survivors who to date have not been recognised or compensated. The size of this group is currently unknown and the Australian Government has not yet performed any work to understand it. The committee also notes that the question of how these unrecognised thalidomide survivors might be able to be compensated has not yet been determined.

4.34 In the committee's final report it will consider what types of financial support thalidomide survivors require and the process by which those supports should be determined.

Government responses to thalidomide in other countries

4.35 Thalidomide survivors indicated to the committee that the Australian response to thalidomide malformations has been less comprehensive than the responses in other countries.⁴⁷ This section outlines some of the approaches that have been taken in other countries to support thalidomide survivors and provides options that could be considered in Australia.

4.36 The payments and supports detailed below are only those provided by governments and does not include supports that thalidomide survivors may be receiving from the distributor or manufacturer in addition to these payments.

⁴⁶ Professor Janet McCredie, *Committee Hansard*, 31 January 2019, p. 7; Professor Neil Vargesson, *Committee Hansard*, 31 January 2019, p. 7.

⁴⁷ See, for example: Name withheld, *Submission 37*, [p. 2]; Name withheld, *Submission 38*, [p. 4].

Lump sum compensation or one off capitalisation upon recognition

- 4.37 Some countries have supported their thalidomide survivors with lump sum payments or one-off capitalisation to allow thalidomide survivors to invest in supports.
- 4.38 Canada, Ireland, Germany, Spain and Sweden all provide examples of this form of assistance, although the quantum provided has differed in each country.⁴⁸

Lump sum by assessed level of disability

- 4.39 Lump sums that have been provided to thalidomide survivors have been provided according to an assessed level of disability in Ireland, Germany and Spain.
- 4.40 Irish and German thalidomide survivors were provided with a one-off payment according to an assessed level of disability in the early 1970s. The Irish State Claims Agency report into Compensation for Thalidomide Survivors delivered in 2010 notes that Irish thalidomide survivors received lump sum payments from both the German and Irish Governments in 1972 and 1973 respectively.⁴⁹
- 4.41 These payments were provided on a scale according to the thalidomide survivor's level of disability. According to the Irish State Claims Agency, the lump sums provided by the German Government varied between DM7500 (IR£1250) and DM25 000 (approximately IR£4200) and the amounts provided by the Irish Government varied between IR£6,600 and IR£21,300.⁵⁰
- 4.42 Germany continues to provide its one-off capital compensation according to the thalidomide survivor's level of disability. Over the course of the past decade, Germany has increased the pensions and benefits available to thalidomide survivors four times.⁵¹ Since 2017, newly recognised thalidomide

⁴⁸ Thalidomide Victims Association of Canada, *Submission 59*, [p. 1]; State Claims Agency (Ireland), *Compensation for Thalidomide Survivors*, April 2010, [p. 1]; Contergan Foundation, *Benefits of the Contergan Foundation*, 2019, https://www.contergan-infoportal.de/stiftung/leistungen_der_conterganstiftung/ (accessed 11 January 2019); Global Regulation, *Royal Decree 1006/2010, Of 5 August, Establishing the procedure for granting aid is regulated to people affected by thalidomide in Spain during the period 1960 – 1965*, <https://www.global-regulation.com/translation/spain/1439622/royal-decree-1006-2010%252c-of-5-august%252c-establishing-the-procedure-for-granting-aid-is-regulated-to-people-affected-by-thalidomide-in-spain-during-th.html> (accessed 22 January 2019); Thalidomidestory.com, *Sweden and other Scandinavian countries*, <http://thalidomidestory.com/story/about-the-drug-thalidomide/distribution-marketing/sweden/> (accessed 22 January 2019).

⁴⁹ State Claims Agency (Ireland), *Compensation for Thalidomide Survivors*, April 2010, pp. 6–7.

⁵⁰ State Claims Agency (Ireland), *Compensation for Thalidomide Survivors*, April 2010, pp. 6–7.

⁵¹ Deutscher Bundestag, [Erster Bericht der Bundesregierung über die Auswirkungen des Conterganstiftungsgesetzes sowie über die gegebenenfalls notwendige Weiterentwicklung dieser Vorschriften](#), Drucksache 18/8780, 09 June 2016, p. 4.

survivors receive between €1278 and €12 782 depending on their assessed level of disability.⁵²

- 4.43 In 2010, Spain provided thalidomide survivors with a one-off lump sum according to their degree of disability. Under this payment thalidomide survivors received €30 000, €60 000, €80 000 or €100 000 provided they had been assessed by an autonomous government health institute and were able to provide certain documentation that demonstrated their identity and proof of their mother's residence in Spain between 1960 and 1965.⁵³
- 4.44 The Thalidomide Group Australia has requested that the Australian Government consider a one-time payment of up to \$500 000 depending upon the thalidomide survivor's assessed level of disability.⁵⁴

Fixed lump sum

- 4.45 Canada and Sweden on the other hand, have provided a fixed lump sum to all thalidomide survivors regardless of level of assessed disability.
- 4.46 Canada has provided its thalidomide survivors with a number of rounds of compensation. In 1990 the Canadian Government established the Extraordinary Assistance Plan. The Extraordinary Assistance Plan was a one-time extraordinary payment to survivors that averaged \$65 000 to provide 'special transportation, housing or other needs not covered by provincial assistance programs'.⁵⁵ The Thalidomide Victims Association of Canada noted that this money was spent 'almost immediately' on adaptations to cars, homes and workplaces and on technical devices that were designed to help with zippers and buttons ect.⁵⁶
- 4.47 In 2015, the Canadian Government announced 'an immediate tax-free lump sum payment of \$125 000 to each survivor to help cover urgent needs'.⁵⁷
- 4.48 In January 2019, the Canadian Government announced that it would increase the lump sum payment to newly recognised thalidomide survivors from \$125 000 to \$250 000 and would pay all recognised survivors an additional

⁵² Contergan Infoportal, Capital Compensation, https://www.contergan-infoportal.de/finanzen_recht/kapitalentschaedigung/ (accessed 22 January 2019).

⁵³ Global Regulation, Royal Decree 1006/2010, Of 5 August, Establishing the procedure for granting aid is regulated to people affected by thalidomide in Spain during the period 1960 – 1965 (accessed 22 January 2019).

⁵⁴ Thalidomide Group Australia, *Submission 1*, p. 3.

⁵⁵ Thalidomide Victims Association of Canada, *Submission 59—Attachment 1*, p. 5.

⁵⁶ Thalidomide Victims Association of Canada, *Submission 59—Attachment 1*, p. 5.

⁵⁷ Thalidomide Victims Association of Canada, *Submission 59*, [p. 1].

\$125 000.⁵⁸ Announcing the increase, the Minister of Health advised that the tax free lumps sum payment was to help thalidomide survivors 'cover urgent care needs'.⁵⁹

- 4.49 According to Thalidomidestory.com, in 2005 Swedish thalidomide survivors received a one-time payment of €55 000 per person from the Swedish Government.⁶⁰

Ongoing support payments

- 4.50 In addition to lump sum payments, some governments have chosen to provide an annual or monthly allowance or pension to thalidomide survivors. Countries who have adopted this form of support include Germany, Canada and Ireland.

Administered trusts or funds

- 4.51 In some cases, governments have preferred to provide money to a foundation or trust that has been established either by the distributor in association with thalidomide survivors or by government to provide certain functions. In some cases the trust can simply act as a conduit between the source of the funds and the thalidomide survivors and in other cases the body can be used as a vehicle to conduct research and to provide services that may assist thalidomide survivors.

United Kingdom

- 4.52 An example of a trust that was established by a distributor is The Thalidomide Trust in the United Kingdom. The Thalidomide Trust has operated in the United Kingdom since 1973 when it was originally established as part of the settlement between Distillers Company Ltd and British thalidomide survivors.⁶¹
- 4.53 Despite this compensation being provided, the UK Thalidomiders Campaign Team advised that it was insufficient to cater to the needs of most thalidomide survivors. Reflecting on this, the UK Thalidomiders Campaign Team told the committee:

⁵⁸ Ingrid Peritz, 'Government opens door to new requests from Canadians who say they are thalidomide survivors', *The Globe and Mail*, 9 January 2019, <https://www.theglobeandmail.com/politics/article-new-program-for-canadian-thalidomide-survivors-aims-to-help-with-costs/> (accessed 14 January 2019).

⁵⁹ Health Canada, *Minister of Health announces new financial support program for eligible Canadian thalidomide survivors*, 9 January 2019, <https://www.canada.ca/en/health-canada/news/2019/01/minister-of-health-announces-new-financial-support-program-for-eligible-canadian-thalidomide-survivors.html> (accessed 22 January 2019).

⁶⁰ Thalidomidestory.com, *Sweden and other Scandinavian countries* (accessed 22 January 2019).

⁶¹ Miss Argy, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 10; Thalidomide Group Australia, *Submission 1*, p. 25.

These inadequate compensatory sums from the Thalidomide Trust have never been enough to allow Thalidomiders to invest properly in their special needs. Adaptations such as foot-steering or adapting a vehicle to be driven from the wheelchair have been too expensive to afford... Expensive kitchen or bathroom adaptations were financially beyond the reach of most.⁶²

4.54 In addition to sums paid to offset tax already paid, the British Government made contributions to the Thalidomide Trust in 1996, 2010 and 2012.⁶³

4.55 In 2010, the British Health Minister Mike O'Brien MP announced that the government would contribute £20 million to the Thalidomide Trust as part of a pilot scheme to help meet the health needs of survivors.⁶⁴ The pilot scheme empowered the Thalidomide Trust to provide money to survivors for a broad range of health related expenses including:

- Independent mobility – anything that helps you to lead an independent life, and reduces your vulnerability to harm (vehicles, vehicle adaptations, wheelchairs, taxi-ride etc).
- Home adaptations – anything to allow you to lead a safe and independent life in your own home as far as possible, with subjecting yourself to unnecessary stress or strain, or doing things that could be harmful.
- Communications technology – systems and things to help you maintain your connection to people and the world at large, and again to protect your body (including sensory organs) from harm and vulnerability.
- Medical treatment costs – can be any kind of therapy, private health care, operations or rehabilitation if not already provided by the [National Health Service].
- Respite – therapeutic breaks for the individual and for their carers.
- Personal assistance – including care in the general sense, but also for a whole range of tasks needed at home or work that you would normally do if you didn't have a disability, but cannot – or would involve putting your body at risk of further damage.
- Social activities – anything to help get you out, or reduce isolation and improve your mental and physical well-being.⁶⁵

4.56 Miss Michaelina Argy, Deputy Chair of the National Advisory Council to the Thalidomide Trust explained that the Thalidomide Trust distributed the

⁶² UK Thalidomiders Campaign Team, *Submission 4*, [p. 3].

⁶³ Thalidomide Group Australia, *Submission 1*, pp. 25–26.

⁶⁴ Rt Hon Mike O'Brien, The Minister of State, Department of Health, *House of Commons Hansard* (UK), 14 January 2010, column 859.

⁶⁵ UK Thalidomiders Campaign Team, *Submission 4*, pp. 4–5.

£20 million in accordance with the points system that had established in 1973 to indicate a survivor's level of disability for compensation purposes.⁶⁶

- 4.57 One survivor who lives in the United Kingdom told the committee that by providing a health grant that can be spent outside of the National Health Service, the government was explicitly recognising that thalidomide survivors have special needs that the regular health service cannot adequately accommodate.⁶⁷
- 4.58 In 2012, the Government of the United Kingdom agreed to contribute an additional £80 million over 10 years to the Thalidomide Trust.⁶⁸
- 4.59 In 2017 the Government of the United Kingdom moved to ensure that the amounts survivors received from the Thalidomide Trust were not assessed in determining whether they were eligible for other state benefits.⁶⁹

Japan

- 4.60 In 1974, Japanese thalidomide survivors reached a settlement with the distributor, Dai Nippon Pharmaceutical and the Japanese Government.⁷⁰
- 4.61 To distribute the settlement, the Japanese Government has established a national centre known as Ishizue.⁷¹ Ishizue operates on a tri-partite basis between the distributor, the Japanese Ministry of Health, Labor and Welfare and Ishizue.⁷² Today, the Ishizue does far more than distribute payments, it coordinates projects to support thalidomide survivors and raise awareness about their needs.
- 4.62 To support thalidomide survivors the Ishizue manages the following projects:
- consultation and support on health management and treatment for thalidomide survivors;
 - paying pensions to thalidomide survivors four times per year;
 - conducting research on the effects of thalidomide;

⁶⁶ Miss Argy, Deputy Chair, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 9.

⁶⁷ Name withheld, *Submission 32*, [p. 1].

⁶⁸ Thalidomide Victims Association of Canada, *Submission 59—Attachment 1*, [p. 4]; Gov.UK, Health grant awarded to victims of thalidomide, 20 December 2012, <https://www.gov.uk/government/news/health-grant-awarded-to-victims-of-thalidomide> (accessed 14 January 2019).

⁶⁹ Miss Argy, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 9.

⁷⁰ State Claims Agency (Ireland), *Compensation for Thalidomide Survivors*, April 2010, p. 11.

⁷¹ State Claims Agency (Ireland), *Compensation for Thalidomide Survivors*, April 2010, p. 11.

⁷² Ishizue, *Business Plan for fiscal year 2018*, p. 5 <http://www008.upp-sonet.ne.jp/ishizue/file/2018jigyouseikaku.pdf> (accessed 24 January 2019).

- consulting on housing remodelling, auxiliary supports and advocates for disability supports (including running a program to support disabled driving);
 - advocating for policies to prevent damage related to drugs and their side-effects; and
 - operating a mutual assistance forum to exchange information with other thalidomide survivor groups and organising events.⁷³
- 4.63 As part of its health consultation, Ishizue provides referrals, medical information to doctors, assists with medical expenses and consults with survivors on how they can best live independent lives.⁷⁴ Some of the forms of independence that are listed in the 2018 business plan include living assistance and housing improvement, assistance with the costs of sign language interpreters and domestic assistance.⁷⁵
- 4.64 Ishizue also conducts research 'with the objective of grasping the actual condition' of thalidomide survivors.⁷⁶

Canada

- 4.65 In 2015, the Canadian Government established the Thalidomide Survivors Contribution Program. The Thalidomide Survivors Contribution Program was outsourced to a third party company to:
- assess and reassess the health status of thalidomide survivors;
 - deliver ongoing annual support payments;
 - manage the Extraordinary Medical Assistance Fund; and
 - determine the eligibility of people who self-identify as thalidomide survivors.⁷⁷
- 4.66 The ongoing support payments in Canada are paid on a sliding scale according to the survivor's level of disability. Survivors can apply to have their health reassessed if they think that their level of functionality has decreased since their previous assessment.⁷⁸
- 4.67 The Extraordinary Medical Assistance Fund can be used to assist with specialised health support costs and home and vehicle modifications for

⁷³ Ishizue, *Business Plan for fiscal year 2018*, pp. 4–9.

⁷⁴ Ishizue, *Business Plan for fiscal year 2018*, pp. 3–4.

⁷⁵ Ishizue, *Business Plan for fiscal year 2018*, p. 4.

⁷⁶ Ishizue, [Public interest foundation](#) (accessed 23 January 2019).

⁷⁷ Thalidomide Group Australia, *Submission 1*, p. 27; Name withheld, *Submission 22*, p. 3; Thalidomide Victims Association of Canada, *Submission 59*, [p. 1].

⁷⁸ Crawford Class Action Services, *Reassessment Application FAQs*, <http://www.tscp-pcst.ca/faq.html> (accessed 24 January 2019).

thalidomide survivors if they were not already covered under a territory or provincial health plan.⁷⁹

- 4.68 The Extraordinary Medical Assistance Fund was administered by Crawford and Company (Canada) on behalf of the Canadian Government. If thalidomide survivors wish to access the fund, they need to submit an application which would then be assessed.⁸⁰
- 4.69 In January 2019, the Canadian Health Minister announced that to account for 'an anticipated increase in the number of recognized thalidomide survivors' the Emergency Medical Assistance Fund would be increased from C\$500 000 to C\$1 000 000 per year.⁸¹

Direct payments

- 4.70 Germany provides thalidomide survivors with two annual payments: one is an annual basic allowance and the other is a payment that is scaled according to the thalidomide survivor's level of disability to cover specific needs.⁸²
- 4.71 An English translation of The Law on the Contergan Foundation for Disabled People as amended by the Fourth Amendment 2017 available on the Contergan Foundation's website provides that each thalidomide survivor is entitled to a basic annual allowance of €4800.⁸³ Insofar as the committee is aware, there is no restriction on how that allowance can be spent.
- 4.72 In addition, since 2009 most German thalidomide survivors have been entitled to an annual 'special payment'.⁸⁴ In Germany, thalidomide survivors are

⁷⁹ Thalidomide Victims Association of Canada, *Submission 59—Attachment 1*, p. 7; Health Canada, *Thalidomide Survivors Contribution Program*, <https://www.canada.ca/en/health-canada/services/thalidomide-survivors-contribution-program.html?wbdisable=true> (accessed 14 January 2019).

⁸⁰ Crawford Class Action Services, *Thalidomide Survivors Contribution Program*, <http://www.tscp-pcst.ca/homeeng.html> (accessed 22 January 2019). The committee understands that administration of this program has since been relocated.

⁸¹ Health Canada, *Minister of Health announces new financial support program for eligible Canadian thalidomide survivors*, 9 January 2019, <https://www.canada.ca/en/health-canada/news/2019/01/minister-of-health-announces-new-financial-support-program-for-eligible-canadian-thalidomide-survivors.html> (accessed 22 January 2019).

⁸² Contergan Inforportal, *Special Payment*, https://www.contergan-infoportal.de/finanzen_recht/jaehrliche_zahlungen/sonderzahlung/ (accessed 22 January 2019).

⁸³ The Law of the Contergan Foundation for Disabled People as amended by the Fourth Amendment 2017 (Germany), §13(2). See Contergan Infoportal, *Thalidomide Foundation Act*, https://www.contergan-infoportal.de/finanzen_recht/rechtsgrundlagen/conterganstiftungsgesetz/ (accessed 8 February 2019).

⁸⁴ The Law of the Contergan Foundation for Disabled People as amended by the Fourth Amendment 2017 (Germany), §13(1).

assessed according to their level of disability on a 100 point scale.⁸⁵ Thalidomide survivors who have a score of more than 10 are entitled to a 'special payment' if the Contergan Foundation's assets can support it.⁸⁶ These payments range between €876 and €9900 per year depending on the survivor's level of assessed disability.

- 4.73 The English version of the law on the Contergan Foundation website provides that the 'special payment' is made to cover 'specific needs'. It is not clear if that term imposes a restriction on what the funds can be used for.⁸⁷

Monthly payments

- 4.74 The German, Italian and Austrian Governments have provided thalidomide survivors with monthly payments.
- 4.75 In Germany, thalidomide survivors receive a monthly Contergan pension of between €662 and €7480 depending upon the survivor's level of disability.⁸⁸ As noted above, this amount has been increased four times in the last decade and is increased each year. The English translation of the law requires the Minister to adjust the amount of the Contergan pension 'at the same percentage the statutory pension insurance is changed'.⁸⁹
- 4.76 The Italian and Austrian Governments have only provided support to their thalidomide survivors relatively recently. Italy first provided monthly pensions in 2007 and Austria commenced paying monthly pensions in July 2015.⁹⁰
- 4.77 According to Thalidomidestory.com, Austria has two groups of thalidomide survivors who have been compensated: one group of 12 thalidomide survivors are compensated through the German Government system and another group of 25 thalidomide survivors that started receiving payments from the Austrian

⁸⁵ Thalidomide Victims Association of Canada, *Submission 59—Attachment 2*, p. 61.

⁸⁶ Contergan Inforportal, Special Payment.

⁸⁷ A report of the Deutscher Bundestag in 2016 indicated that there had been legal action in an administrative court to determine what the money could be spent on. At the time the report was released the issue had not been resolved. The Contergan Foundation declined the committee's invitation to participate in the inquiry. See Deutscher Bundestag, [Erster Bericht der Bundesregierung über die Auswirkungen des Conterganstiftungsgesetzes sowie über die gegebenenfalls notwendige Weiterentwicklung dieser Vorschriften](#), 9 June 2016, pp. 8–10 (accessed 22 January 2019).

⁸⁸ Contergan Infoportal, *Benefits of the Contergan Foundation* (accessed 22 January 2019).

⁸⁹ The Law of the Contergan Foundation for Disabled People as amended by the Fourth Amendment 2017 (Germany), §13(2).

⁹⁰ Tech2.org/Italy, 'Thalidomide victims, seven days to claim compensation', 19 December 2017, <https://tech2.org/italy/thalidomide-victims-seven-days-to-claim-compensation/> (accessed 22 January 2019).

Government in 2015. The Austrian Government payments are reported to be approximately €425.80 per month.⁹¹

Comments from overseas survivors in receipt of assistance

- 4.78 The committee received submissions and correspondence from thalidomide survivors from various parts of the world to explain how support from the government in their country had helped to improve their lives.⁹²
- 4.79 In particular, the committee received correspondence from a number of German thalidomide survivors. One survivor summarised that the increase in German Government compensation allowed German thalidomide survivors the ability to have sufficient physiotherapy,⁹³ make modifications to their homes and cars,⁹⁴ pay for carers,⁹⁵ purchase special aids⁹⁶ and wheelchairs and to save for old age.⁹⁷
- 4.80 Another German thalidomide survivor told the committee that it is only with the additional support from the German Government that they are able to live independently.⁹⁸ For these survivors, the increased compensation allowed them to increase their financial security, independence and quality of life and to do so with less pain.⁹⁹
- 4.81 The committee received similar comments from Canadian thalidomide survivors who received the lump sum payments and pensions. One survivor told the committee that receiving the pension had put their mind at ease as they aged:

I'm now able to afford physiotherapy for all my joint problems. I'm also able to have some adaptations to my home, to make it a lot safer for me. Just knowing I have this pension, gives me piece of mind [sic] as I get

⁹¹ Thalidomidestory.com, Austria, <http://thalidomidestory.com/story/about-the-drug-thalidomide/distribution-marketing/austria/> (accessed 23 January 2019).

⁹² See, for example: Name withheld, *Submission 32*, p. 1; Name withheld, correspondence received 11 October 2018, [p. 1]; Name withheld, correspondence received 12 October 2018, [p. 1].

⁹³ See, for example: Name withheld, correspondence received 10 October 2018, [p. 1].

⁹⁴ See, for example: Name withheld, correspondence received 8 October 2018, [p. 1].

⁹⁵ See, for example: Name withheld, correspondence received 12 October 2018, [p. 1]; Name withheld, correspondence received 10 October 2018, [p. 1]; Name withheld, correspondence received 8 October 2018, [p. 1].

⁹⁶ Name withheld, correspondence received 13 October 2018, [p. 1].

⁹⁷ Name withheld, *Submission 47*, [p. 1].

⁹⁸ Name withheld, *Submission 30*, [p. 1].

⁹⁹ Name withheld, *Submission 47*, [p. 1]. See also Name withheld, *Submission 30*, [p. 1]; Name withheld, correspondence received 11 October 2018, [p. 1]; Name withheld, correspondence received 9 October 2018, [p. 1]; Name withheld, correspondence received 8 October 2018, [p. 1].

older, and knowing that I will need more help to have the best quality of life later.¹⁰⁰

- 4.82 Part of the reason these pensions appear to mean so much to thalidomide survivors is that without them, thalidomide survivors have not been able to properly invest in their health. Miss Argy from the National Advisory Council to the Thalidomide Trust in the United Kingdom argued that the British experience demonstrated that it was necessary to provide survivors with lump sum payments to allow them to invest in their health and mobility needs:

What I can advise from the UK situation is that Australian thalidomiders will need a substantial lump sum to enable them to pay for major adaptations and changes that they need to make now, a catch-up for the previous inability to invest properly in their needs, followed by an annual income for them to spend freely, without encumbrance, on the multitude of day-to-day things that will help them to stop any further decline in their health or mobility.¹⁰¹

- 4.83 Thalidomide survivors from the United Kingdom who submitted to the inquiry considered that the health grant had made a significant difference to their health and independence.¹⁰² One survivor told the committee that with the financial support they received, they were able to live independently and stay in control of their pain.¹⁰³

- 4.84 Another survivor from the United Kingdom told the committee that the health grant had helped to extend their working life:

...the government grant has made a huge difference to me. It's allowed me to have physiotherapy privately whenever I need it, massage therapy privately whenever I need it and Pilates lessons on a one-to-one to enable me to carry on working without pain. It pays for assistance in the home...so I can carry on living in my own home.¹⁰⁴

- 4.85 The survivor also noted that the grant had helped to modify her garden, adapt her bathroom to allow her to look after her own personal hygiene and allowed her to pay for taxis because she is now unable to drive or manage on public transport.¹⁰⁵

- 4.86 Miss Argy from the National Advisory Council to the Thalidomide Trust told the committee that the grant was successful because it allowed survivors to spend money on supports that they needed, even if the reason they were

¹⁰⁰ Name withheld, correspondence received 14 September 2018, [p. 1].

¹⁰¹ Miss Argy, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 9.

¹⁰² See for example: Name withheld, *Submission 29*, [p. 1]; Name withheld, *Submission 32*, [p. 1].

¹⁰³ Name withheld, *Submission 29*, [p. 1].

¹⁰⁴ Name withheld, *Submission 32*, [p. 1].

¹⁰⁵ Name withheld, *Submission 32*, [p. 1].

needed may not be obvious to a person without the disability. Miss Argy provided some examples for the committee about how heating and cooling could affect thalidomide survivors' independence:

If you're very hot and you're sweating then, as a woman, putting your underwear on is impossible...you need a carer to dress you. In this country, if we pay for air conditioning we can dress ourselves. If we went to our benefits system and said 'I would like you to pay for my air conditioning,' they'd laugh us out of the house...I and people like me and short-armed people, pay extra to have underfloor heating so that I can walk around in bare feet and use my feet at all the times of the day and night...If I can have extra-warm flooring, if I can have air conditioning, I can manage some of that stuff on my own.¹⁰⁶

- 4.87 The Thalidomide Victims Association of Canada advised the committee that the package Canadian thalidomide survivors received from the Canadian Government similarly provided survivors with physical independence and the independence to make their own choices. After living without the support, the Thalidomide Victims Association of Canada described what the support package meant for Canadian survivors:

This financial support took into consideration the broad range of needs that survivors have and gave us the independence to make our own choices. For many Canadian thalidomide survivors this support was life-altering and made it possible for them to finally live with dignity.¹⁰⁷

Perspective of Australian thalidomide survivors

- 4.88 Australian thalidomide survivors who submitted to this inquiry considered that additional financial support from the Australian Government would allow them the ability to invest in their health.¹⁰⁸ As noted in Chapter 2, many thalidomide survivors and their families have led lives that have been less economically beneficial than if they had not had their thalidomide injuries. As a result many Australian thalidomide survivors have felt less able to invest in their care.
- 4.89 Thalidomide survivors advised the committee that if they had access to a lump sum they would be able to purchase the services that they needed rather than attempting to rely on other services, such as the NDIS that may take longer to procure the same services. For example, access to a lump sum may alleviate the problems faced by the survivors, outlined in Boxes 3.1 and 3.2, in procuring the services that they needed.¹⁰⁹

¹⁰⁶ Miss Argy, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, pp. 12–13.

¹⁰⁷ Thalidomide Victims Association of Canada, *Submission 59*, [p. 1].

¹⁰⁸ See, for example: Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 9*, [p. 2].

¹⁰⁹ See, for example: Mark, *Committee Hansard*, 31 January 2019, p. 20.

- 4.90 Survivors who spoke to the committee considered that some additional compensation from the Australian Government would allow them the freedom to invest in their care.¹¹⁰
- 4.91 Submitters and witnesses who engaged with the committee often commented on the cost of healthcare in Australia. As noted above, thalidomide survivors require, and are likely to continue to require, surgery and medical assistance as they age. The Thalidomide Group Australia and some thalidomide survivors, including some who made confidential submissions to the inquiry, requested a Gold Card¹¹¹ or something similar to assist with the cost of health care.¹¹²
- 4.92 Concerns about the cost of healthcare are not peculiar to Australia and different governments have developed different ways to meet the health needs of survivors. This list is not a comprehensive list of the health programs that have been offered to survivors around the world, but it is an illustration of the types of health supports that governments in comparative countries have offered their survivors.
- 4.93 As noted above, Australian thalidomide survivors are struggling with health concerns and it is likely that they will require additional supports as they age. Australian thalidomide survivors advised the committee that if they had a health grant or a medical fund, then they would have the flexibility to pay for medical procedures,¹¹³ equipment,¹¹⁴ adapt their homes¹¹⁵ and pay for care providers according to their individual needs.¹¹⁶
- 4.94 One survivor told the committee that a health grant or funds that they could put toward their care would allow them to access private care:

I would love to have private health/ dentistry and not be at the mercy of the public health system as I feel that when things get bad for me health

¹¹⁰ See, for example: Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 49*, p. 4.

¹¹¹ A Gold Card is a Department of Veterans' Affairs health card that entitles veterans and former members of the Australian Defence Force access to a range of public and private health services at the department's expense: Department of Veterans' Affairs, *Veterans' health cards*, <https://www.dva.gov.au/health-and-wellbeing/veterans-health-cards> (accessed 14 January 2019).

¹¹² See, for example: Thalidomide Group Australia, *Submission 1*, p. 3; Name withheld, *Submission 38*, [p. 3].

¹¹³ Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 20*, [p. 2]; Name withheld, *Submission 21*, p. 1; Name withheld, *Submission 27*, [p. 1].

¹¹⁴ Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 15*, [p. 3]; Name withheld, *Submission 27*, [p. 1]; Name withheld, *Submission 35*, p. 1; Name withheld, *Submission 41*, [p. 3]; Name withheld, *Submission 42*, [p. 6].

¹¹⁵ Rick, *Committee Hansard*, 2 November 2018, p. 15; Name withheld, *Submission 6*, p. 5; Name withheld, *Submission 20*, [p. 2]; Name withheld, *Submission 21*, p. 1; Name withheld, *Submission 41*, [p. 3]; Name withheld, *Submission 42*, [p. 3].

¹¹⁶ Name withheld, *Submission 20*, [p. 2]; Name withheld, *Submission 42*, [p. 5].

wise it won't just be one thing, it will be a whole bunch of things go bad in rapid succession.¹¹⁷

Tax relief and other government programs

- 4.95 Some governments have found more direct ways to provide services to thalidomide survivors.
- 4.96 For example in Sweden, Norway and Denmark thalidomide survivors are eligible to receive free wheelchairs, between four and 24 hours per day of personal assistance, free car adaptation and free assistive technology in the workplace.¹¹⁸
- 4.97 In Italy, the government added 'thalidomide syndrome' to a list of chronic diseases, which, according to the Italian Thalidomide Association, means that 'all recognised thalidomidicis will be entitled to free health services concerning the control of their condition' although the extent of the services required is determine by the survivor's doctor.¹¹⁹
- 4.98 The Irish Government has also allowed thalidomide survivors to receive a disability allowance (at their election), provided survivors with a grant to adapt their vehicles and facilitated their participation in a scheme that exempts them from certain vehicle related taxes.¹²⁰
- 4.99 The committee understands that the Irish Government has provided health related supports to its thalidomide survivors, including a medical card without means testing and funding for artificial limbs and appliances.¹²¹
- 4.100 The health boards also reimbursed the parents of thalidomide survivors for medical or legal expenses that they may have incurred after the settlement.¹²²

Apologies

- 4.101 In January 2010, the Government of the United Kingdom apologised to its thalidomide survivors, expressing 'deep sympathy for the injury and suffering endured by all those affected'.¹²³ In the House of Commons it was recognised that the statement of regret and the additional funding were the product of a

¹¹⁷ Name withheld, *Submission 18*, [p. 3].

¹¹⁸ State Claims Authority (Ireland), *Compensation for Thalidomide Survivors*, April 2010, p. 10.

¹¹⁹ Ministry of Health (Italy), [The new essential levels of assistance](#), p. 11 (accessed 23 January 2019).

¹²⁰ State Claims Authority (Ireland), *Compensation for Thalidomide Survivors*, April 2010, pp. 8, 15–16; Irish Thalidomide Association, *About Us*, <https://www.thalidomideireland.com/> (accessed 11 January 2019).

¹²¹ State Claims Authority (Ireland), *Compensation for Thalidomide Survivors*, April 2010, p. 8.

¹²² State Claims Authority (Ireland), *Compensation for Thalidomide Survivors*, April 2010, p. 8.

¹²³ Mr Mike O'Brien, The Minister of State, Department of Health, *House of Commons Hansard* (UK), 14 January 2010, column 860.

'long-standing and concerted campaign' by thalidomide survivors, the Thalidomide Trust and its National Advisory Council.¹²⁴

4.102 Miss Argy, a British thalidomider and Deputy Chair of the National Advisory Council to the Thalidomide Trust, expressed the deep impact that the statement had on British survivors:

It was the most marvellous, magical experience to sit there and hear the Minister in the House of Commons issue that statement of regret. It's like the world stopped for the time he was talking.¹²⁵

4.103 Many Australian survivors and their supporters who submitted to the inquiry called for the Australian Government to provide an apology.¹²⁶

4.104 As one survivor told the committee:

From all these politicians, I have been eagerly awaiting one word and that is 'sorry'—sorry for the drugs being allowed in Australia, sorry for the families that have been affected by the drugs, sorry for the survivors who have had to live with these disabilities.¹²⁷

4.105 Some survivors told the committee that receiving an apology would help to alleviate some of the emotional pain that survivors and their families have experienced.¹²⁸ For others, an apology would help to recognise the role that the Australian Government played in their lives.

4.106 Mary, another survivor told the committee that an apology would recognise the role that the Australian Government had played in thalidomide in Australia:

It's about acknowledgement. It is as much about saying, 'We are sorry we ignored you. We are sorry we failed you in the first instance.' It is admitting their role in our lives.¹²⁹

4.107 The Department of Health advised the committee that no advice has, to date, been provided to the Minister about an apology.¹³⁰

¹²⁴ Mr David Heath, *House of Commons Hansard* (UK), 14 January 2010, column 862.

¹²⁵ Miss Argy, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 11.

¹²⁶ See, for example: Thalidomide Group Australia, *Submission 1*, p. 3; Name withheld, *Submission 17*, [p. 1]; Name withheld, *Submission 23*, [p. 3]; Name withheld, *Submission 27*, [p. 1]; Name withheld, *Submission 39*, [p. 1].

¹²⁷ Nola, *Committee Hansard*, 2 November 2018, p. 21.

¹²⁸ Nola, *Committee Hansard*, 2 November 2018, p. 22.

¹²⁹ Mary, *Committee Hansard*, 2 November 2018, p. 22.

¹³⁰ Ms Lisa Studdert, Deputy Secretary, Department of Health, *Committee Hansard*, 2 November 2018, pp. 29–30.

Committee view

4.108 The committee understands that other countries have provided compensation to their thalidomide survivors in the form of lump sum payments, monthly or annual pensions, health care grants or funds and provided for access to other special benefits that may assist survivors.

4.109 The committee accepts that there is a broad scope for Australia to do more to assist its survivors. The committee understands that the Australian Government commissioned a report from Maddocks Lawyers to help understand the options that may be available to the Commonwealth. The committee notes that this report has not yet been released and that to date the Australian Government has resisted its release on the grounds of public interest immunity.¹³¹ In its final report, the committee will consider the extent to which the options described above may be suitable in an Australian context.

¹³¹ Senator the Hon. Bridget McKenzie, [correspondence to Senator the Hon. Scott Ryan, President of the Senate](#), 15 August 2018.

Chapter 5

Conclusion and recommendations

Many of us who survived missed out on opportunities in life because of the deformities. Some of these opportunities are having a life-long relationship with someone they love, having children, pursuing a career, and being able to earn good money, pursuing their dreams and following their passions...without the stares, the pointing, the whispering and, most of all, the pain and suffering throughout their lives. The government cannot just turn a blind eye to the injustice we have had to endure. We are not dead yet. We are very much alive and want to live the rest of our lives as best we can.¹

- 5.1 Thalidomide has had, and continues to have, an all-encompassing effect on the lives of survivors and their families. The committee recognised that survivors and their families have lived with the consequences of thalidomide throughout their lives.

Fifty years of fighting

- 5.2 Since thalidomide survivors were exposed to thalidomide in utero, survivors have had to struggle to overcome adversity. As children, some survivors were institutionalised, required multiple surgeries, and spent long periods of time seeking medical care or disability assistance. The childhood opportunities of survivors were often determined by the limitations of their physical impairments. Survivors faced difficulty in accessing education, forming social connections and finding employment. Bullying was a common occurrence, the effects of which have stayed with survivors into adulthood. Some survivors have been further abused and marginalised later in life.
- 5.3 Thalidomide survivors have complex health conditions, affecting them both physically and psychologically. The committee is aware that some survivors died prematurely as a result of thalidomide complications. The committee heard that survivors often need assistance in performing routine tasks, such as getting dressed or toileting. Survivors have been discriminated against in accessing work and many have been forced to retire due to their deteriorating health. As survivors age, their thalidomide injuries are worsening as they are experiencing the effects of wear and tear and premature ageing.
- 5.4 Survivors have fought hard to live life on their own terms to reach their potential, particularly in education, work and family life. For this inquiry, it has been necessary for the committee to consider the impacts thalidomide has had on survivors and their families, and the disadvantages survivors continue to face, to adequately understand the support requirements of Australia's

¹ Joanne, *Committee Hansard*, 31 January 2019, p. 24.

thalidomide survivors. This led to the committee receiving and hearing considerable distressing evidence. Yet it is clear to this committee that survivors simply want to live an independent and dignified life, to greatest extent possible. Survivors have battled to maintain their independence, to gain acceptance, inclusion and now support.

- 5.5 Survivors have been inadequately supported in living life independently, and maintaining their quality of life in the face of significant health issues and physical impairments. As thalidomide survivors age, their support requirements will increase, and the committee is aware survivors' health is declining at an accelerated rate. The committee is concerned that evidence from survivors indicates that their current and future support arrangements are inadequately provided for, and that survivors' wellbeing is adversely affected.

Compensation and the role of the Australian Government

- 5.6 The committee acknowledges that Australia's recognised thalidomide survivors have received some compensation and financial support. However, payments that they have received to date were calculated based on legal factors, not an evaluation of the true cost of what thalidomide survivors might need to live independently with dignity with their significant disabilities.
- 5.7 It is clear to the committee that the payments that thalidomide survivors have received to date are not commensurate with the cost of the supports that they need now. It is also clear that as the Diageo payments do not increase with inflation, the financial support that they are currently receiving will become increasingly inadequate to meet their needs.
- 5.8 The committee recognises that, comparative to other countries, Australia has done relatively little to support its thalidomide survivors. In Chapter 4 the committee noted that governments in other countries have provided generous assistance to thalidomide survivors in addition to support that survivors may have been receiving from the distributor. These forms of support have been both financial and non-financial.
- 5.9 The committee considers that the Australian Government should closely consider what it could do to ensure that Australia's thalidomide survivors receive both financial and practical supports commensurate to their needs. The committee's examination of models of support implemented in other countries indicates a wide range of possible approaches that could be taken to support Australian thalidomide survivors.
- 5.10 The committee understands that the Australian Government commissioned a report from Maddocks Lawyers to obtain a comprehensive picture of the Commonwealth's role and the possible options that are open to the Commonwealth. The committee understands that this report may contain important information regarding the role of the Australian Government in

providing improved support and compensation to Australia's thalidomide survivors. The committee strongly encourages the Australian Government to make the report available to the committee.

- 5.11 Australia has two differently compensated groups of recognised thalidomide survivors and potentially a group of unrecognised thalidomide survivors. The committee has received substantial evidence as to the need to revisit the issue of further compensation. To ensure that any Australian Government framework adequately meets the needs of all Australian thalidomide survivors, the committee considers that more work and research needs to be undertaken to determine how that scheme should work. The committee intends to focus on the design of such a scheme in its final report.
- 5.12 Based on the evidence the committee has received to date in this inquiry, there are some steps that the committee considers should be taken immediately.

Coordination and development of further knowledge

- 5.13 Throughout this inquiry, the committee has observed that there appears to be a paucity of knowledge in Australia about thalidomide and its effects on the lives of survivors. The Department of Health, the Department of Social Services and the National Disability Insurance Agency all admitted to having little knowledge about thalidomide survivors and this lack of knowledge and understanding is reflected in the challenges that thalidomide survivors have experienced in obtaining access to government services and payments.
- 5.14 As thalidomide survivors' injuries are caused by a drug and as some thalidomide survivors are likely to require access to aged care services in the near future, the committee considers that the Department of Health should take the lead, in consultation with thalidomide survivors, to establish an inter-departmental working group to develop better knowledge within government departments and to create more transparent pathways and contacts for thalidomide survivors.

Recommendation 1

- 5.15 **The committee recommends that the Department of Health, in consultation with Australia's thalidomide survivors, establish an inter-departmental working group with a view to:**
- **facilitating easier access to existing Australian Government payments and services; and**
 - **conducting or commissioning additional research about the health and other needs of thalidomide survivors in Australia.**
- 5.16 The committee considers that one area that this working group could prioritise is the development of a central contact point within the Department of Health, the Department of Human Services and the National Disability Insurance

Agency. Staff performing these roles should have an understanding of the nature of thalidomide injuries and survivors' experiences and needs and be able to act as a contact and a 'champion' to help thalidomide survivors understand what they may be eligible for and how to apply for it. As thalidomide survivors represent only a small number of people and as the committee understands that something similar has previously existed within the Department of Human Services, the committee considers that this could provide a useful and practical first step.

Recommendation 2

5.17 The committee recommends that a contact point for thalidomide survivors should be established in the Department of Health, the Department of Social Services and the National Disability Insurance Agency.

5.18 Another area that needs to be prioritised is the development of a network of health specialists and practitioners with a specialised knowledge of thalidomide injuries. The committee received evidence that understanding of thalidomide injuries among health practitioners is generally poor and that many practitioners have not encountered thalidomide survivors in their practices. The specialised nature of thalidomide injuries poses particular challenges for even the most routine medical consultation. This underscores the need for a network of health practitioners and specialists to be identified who can treat thalidomide survivors appropriately. Within Australia, it is not clear who the leading physicians or specialists might be or that any substantive research is being done to try and find out. Evidence to the committee to date, is that thalidomide survivors themselves have played a large part in assisting health practitioners to understand their injuries and the implications of these for medical treatment.

5.19 The committee received evidence that relevant health professionals have been located by the Thalidomide Trust in the United Kingdom and by Ishizue in Japan, but it is clear that the Australian Thalidomide Fixed Trust does not have the capacity to carry out this function. The committee considers that identification of relevant health professionals should not be outsourced to thalidomide survivors, but should be undertaken by a properly resourced body.

Recommendation 3

5.20 The committee recommends that the Department of Health work with the relevant professional colleges to identify Australian health practitioners who have, or are prepared to acquire, expertise in treating thalidomide injuries.

5.21 Throughout the course of this inquiry the committee experienced difficulty in identifying health practitioners who were able to assist it. However, the

committee received evidence that there are groups internationally who are willing to assist Australia to build capacity in this area. The committee considers that the Department of Health and the relevant professional colleges should work together to develop a framework to provide funding assistance to enable health practitioners to learn from international experts.

Recommendation 4

5.22 The committee recommends that if adequate relevant expertise does not exist in Australia, the Department of Health work with professional colleges to ensure appropriate funding assistance is available to enable specialists to learn from international experts who already treat thalidomide survivors.

5.23 The committee considers that the working group should commission a study of the health of Australian thalidomide survivors to understand how survivor's health needs change over time. The committee is conscious that Australia's thalidomide survivors have already endured a lifetime of medical assessments and reassessments. The evidence the committee received indicates that thalidomide survivors' health outcomes are deteriorating. The committee has heard evidence that suggests records of previous assessments undertaken in 2010 are scant, but that some of this information may still exist. The committee considers that it would be useful to establish a baseline against which to assess and understand thalidomide survivors' health needs in the future, particularly given the evidence received during this inquiry regarding the effects of early onset ageing on thalidomide survivors.

Recommendation 5

5.24 The committee recommends that the Department of Health conduct a survey of the health of Australia's thalidomide survivors to serve as a baseline assessment for future reference.

Making existing supports work more effectively

5.25 Thalidomide survivors told the committee that they have experienced difficulty accessing a number of payments and services. The committee considers that these difficulties should be closely examined and addressed as a matter of priority.

National Disability Insurance Scheme

5.26 The National Disability Insurance Scheme (NDIS) has been a source of substantial frustration for thalidomide survivors and their families. In Chapter 3 the committee noted that the NDIS has developed a complex disability pathway that may be of some assistance to thalidomide survivors. However, the evidence the committee has received indicates that the NDIS still has some way to go if it is to provide appropriate support to thalidomide survivors. The committee hopes that the establishment of a central point of

contact at the NDIS that can support thalidomide survivors to navigate the NDIS may assist to some degree.

- 5.27 The National Disability Insurance Agency (NDIA) suggested to the committee that it could create a factsheet to educate planners and assessors about thalidomide and thalidomide injuries. The committee considers that while this is a small step it is an important step in the right direction.

Recommendation 6

- 5.28 The committee recommends that the National Disability Insurance Agency create a guide to assessing and planning appropriate supports for thalidomide survivors.**

- 5.29 As noted in Chapter 3, the committee is concerned about thalidomide survivors' supports being reduced by the NDIA. The committee understands that the way the *National Disability Insurance Scheme Act 2013* is drafted requires the NDIA to take compensation into account. In the committee's final report, it will investigate how the Act may need to be amended.

Medical professions

- 5.30 The committee received some very concerning evidence about the conduct of health practitioners and the ways they have dismissed thalidomide survivors. The committee recognises that given the relatively small number of thalidomide survivors, most practitioners will not have treated a thalidomide survivor. Practitioners may have little understanding of the range of thalidomide injuries and what this might mean for the treatment of individual survivors. The committee considers that as the bodies responsible for continuing medical education, the relevant colleges should take steps to raise awareness of thalidomide and thalidomide injuries among their members and incorporate a module on thalidomide and thalidomide injuries into their syllabuses.

Recommendation 7

- 5.31 The committee recommends that the Royal Australian College of General Practitioners, the Royal Australasian College of Physicians and the Australian College of Rural and Remote Medicine take steps to raise awareness of thalidomide and thalidomide injuries, including by incorporating a module on thalidomide injuries in their next round of Continuing Professional Development.**

Future compensation and the final report

- 5.32 This interim report has focused on the effect of thalidomide on survivors and their families. It is clear that thalidomide has affected every part of their lives and continues to affect them and their families.

- 5.33 The committee recognises that thalidomide survivors have waited a long time to be heard. The committee recognises that in tabling this interim report it is asking thalidomide survivors to wait longer still to hear the committee's conclusions on the question of future compensation.
- 5.34 The committee has received compelling and insightful evidence to date, but the evidence it has received has also revealed that there are questions that require further examination. This includes closer consideration of a number of matters that were brought to the committee's attention late in the inquiry.
- 5.35 The committee intends to continue its examination of the response of states and the Commonwealth to thalidomide injuries, including the range of supports Australian governments have provided thalidomide survivors to date. It will also consider any intergovernmental cooperation to address the needs of thalidomide survivors.
- 5.36 As noted in this report, other governments around the world have provided financial and non-financial supports to their thalidomide survivors. In this report the committee has canvassed the options that may be available to inform the provision of additional support for Australian thalidomide survivors. In its final report, the committee will look more closely at this.
- 5.37 At its Sydney hearing the committee attempted to examine the assessment and decision making process that underpinned the financial payments that have been made to date. While the committee has noted some evidence about these assessments and payments in this report, the committee still has an incomplete understanding of the process by which the current support payments were determined. The committee intends to conclude its consideration of these matters in its final report.

Recommendation 8

- 5.38 The committee recommends that the Senate extend the date for the presentation of the final report for this inquiry to 22 March 2019.**

Senator Rachel Siewert
Chair