

Chapter 10

Accessing equipment

Background

10.1 This chapter examines the evidence which the committee received concerning the difficulties faced by palliative care recipients in accessing equipment. As the majority of patients with life limiting illnesses desire to be cared for and pass away in the community or home setting, aids and equipment are necessary to help achieve that goal.

10.2 In the course of the committee's inquiry, much reference was made to the Home and Community Care (HACC) program and its important role in assisting palliative care recipients.¹ Although the HACC program is broader than equipment provision, the evidence the committee received highlighted the important role equipment plays in supporting those patients with life limiting illnesses who are not being cared for in a hospital setting.

The HACC program

What is the HACC program?

10.3 The Commonwealth HACC Program provides services that support older people to be more independent at home and in the community. HACC services include:

- nursing care;
- allied health services like podiatry, physiotherapy and speech pathology;
- domestic assistance, including help with cleaning, washing and shopping;
- personal care, such as help with bathing, dressing, grooming and eating;
- social support;
- home maintenance;
- home modifications;
- assistance with food preparation in the home;
- delivery of meals;

1 The HACC program, which was previously jointly funded by the federal and state and territory governments, became a federal government program from 1 July 2012. HACC services can be accessed by people aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people), who are at risk of premature or inappropriate admission to long term residential care, and carers of older Australians eligible for services under the Commonwealth HACC Program. Source: <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> (accessed 26 September 2012).

- transport;
- assessment, client care coordination and case management;
- counselling, information and advocacy services;
- centre-based day care; and
- support for carers including respite services.²

10.4 The eligibility requirements to enable access to the Commonwealth HACC program require that a person be:

- aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people); and
- at risk of premature or inappropriate admission to long term residential care; or
- a carer of older Australians eligible for services under the Commonwealth HACC Program.³

Recent changes

10.5 The Department of Health and Ageing (DoHA/the department) explained the recent changes that were made to the HACC program and which took effect from 1 July 2012:

From 1 July 2012 the Commonwealth HACC Program will provide funding for basic community care services which support frail older people and their carers, who live in the community and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long term residential care. The target population for the Commonwealth HACC Program are frail older people with functional limitations as a result of moderate, severe and profound disabilities and the unpaid carers of these frail older people. Older people are people aged 65 years and over and Aboriginal and Torres Strait Islander people aged 50 years and over.⁴

10.6 DoHA explained that as a result of the changes the responsibility for the provision of such services to younger people will remain with the state and territory

2 Department of Health and Ageing, Commonwealth Home and Community Care (HACC) Program, <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> (accessed 28 September 2012).

3 Department of Health and Ageing, Commonwealth Home and Community Care (HACC) Program, <http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm> (accessed 28 September 2012).

4 Department of Health and Ageing, answers to questions on notice (question 7) received 23 May 2012.

governments.⁵ The department also informed the committee that the HACC program is not designed to provide specialist palliative care services although those receiving HACC services may in fact be palliative care patients:

The Commonwealth HACC Program does not provide specialist palliative care services as these services continue to be outside the scope of the Program. However, people who are receiving palliative care services may also be part of the Commonwealth HACC target population and therefore may be eligible to receive basic maintenance, support and care services. Commonwealth HACC services may be provided to people receiving palliative care services as long as these services are not expected to be provided as part of the general suite of specialist palliative care services.

People that are in the target population will be assessed to establish the type and extent of their support needs. Services will be provided based on this assessment, the priority of need of the person and the capacity of the service provider to deliver support within existing resources. Support through the Commonwealth HACC Program is also available to carers of eligible people.⁶

10.7 The committee acknowledges that as the recent changes to HACC only took effect from 1 July 2012, it is too soon to tell whether or not they have improved access to services and equipment for the majority of palliative care recipients. However, stakeholders identified a number of areas which at times presented barriers or limitations to the HACC and state run equipment programs. Among these barriers were the need to improve access to equipment, particularly for younger patients including children, and the need for greater regulation of equipment.

10.8 Services for Australian Rural and Remote Allied Health (SARRAH) explained these difficulties succinctly:

In Australia we have a very fragmented and hopeless group of systems in terms of equipment provision across the states... each state has a totally different way of providing equipment to support people in palliative care, in disability and in the acute health system. How people can access equipment depends on the way the states run those. So there is money provided by the Commonwealth to support palliative care equipment but that is usually a

5 State and Territory governments will continue to fund and administer basic community care services for people under 65 years and Aboriginal and Torres Strait Islander people aged under 50 years. This change in responsibility applies to all states and territories except Western Australia and Victoria who are not participating in the reforms to HACC. Basic community care services for frail older people and younger people with disability in Victoria and Western Australia will continue to be delivered under the Home and Community Care Program as a joint Commonwealth-State funded program, until otherwise agreed. Source: Department of Health and Ageing, answers to questions on notice (question 7) received 23 May 2012.

6 Department of Health and Ageing, answers to questions on notice (question 7) received 23 May 2012.

separate pool of equipment that is managed by the states or by the disability sector. It really is a dog's breakfast.⁷

Better access

10.9 The Victorian Palliative Care Special Interest Group of Occupational Therapy Australia (OTA) provided the committee with an example of the practical difficulties patients requiring palliative care have experienced when trying to access equipment either through the HACC program or other state-funded/based programs. They explained that in Victoria, hospitals are required to provide equipment for a 28 day period following a patient's discharge even though the patient may clearly require equipment for a longer period of time:

Hospitals are required to provide equipment for 28 days post discharge... Sometimes that works in palliative care because people can get re-admitted within the 28 days. But it is also dependent very much on service to service.⁸

10.10 OTA further explained that access to equipment may also be affected by the associated hire costs, which are often prohibitive and vary considerably despite the fact that the costs that would be associated with caring for those patients in hospital would be many times more.⁹

10.11 OTA explained that given the prohibitive costs families often incur when hiring equipment, some service providers seek to assist at a financial cost to themselves:

...I do not charge any of my patients for any equipment for palliative care that I have; other hospitals do. I think it is a bit rough being asked to fork out money when there is enough other stuff going on, but other services do. And you have to manage that financially as well. We have a high turnover so it keeps coming back and that is how we manage that. The other patients are charged. If somebody needs something longer, say, an electric hoist at home, we will pay for that for the month. We have no budget to pay for that. We have to but we have no budget. Then the family pick up the cost after that or sometimes they can access money through unassigned bed funds.¹⁰

10.12 The financial barriers to accessing equipment were also raised by Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Reference Group. Dr Hynson explained:

7 Mr Michael Bishop, Life Member, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, pp. 32–33.

8 Ms Deidre Morgan, Senior Occupational Therapist, Palliative Care, Peninsula Health, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 23.

9 Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

10 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 23.

...we have exactly the same issues [as OTA] with families of young children trying to obtain equipment. We have state based organisations and, on the surface, it looks as though you can get equipment but the subsidies have not changed in 15... to 20 years. The total cost for a motorised wheelchair might be \$12,000 to \$15,000, but the contribution from the state might be \$3,000. Then the family has to find the gap. The wheelchair cannot be ordered until the gap is found. So you find families fundraising and having parties to try to get the rest of the money. A good case manager will be trying to source things.¹¹

10.13 Dr Hynson informed the committee that although the hospital program she runs has flexible funds attached to it which enable the hospital to pay the gap for families, the fund was only established after a couple of instances where children died waiting:

A couple of children died waiting for equipment or for handrails to be put in their house so they could get around and, by the time the handrails got there, they had lost the ability to walk. The family was left with this constant reminder. So a couple of bad things happened that ended up with us holding that flexible fund. We have to manage that very tightly.¹²

10.14 Dr Hynson explained the optimism some have in the introduction of the National Disability Insurance Scheme; they see it as a way of ensuring such circumstances do not arise by providing basic services including equipment and supplies for children suffering life limiting illnesses:

We are hoping that perhaps a disability insurance scheme will mean that families do not have to fight for basic supplies. The very disabled kids do not just need a wheelchair, as the OTs were saying; they need a whole lot of other stuff as well. So it [the cost] adds up.¹³

10.15 In addition to long waiting times, the committee also heard of time limits being imposed on the provision of equipment and services. According to SARRAH this is occurring in Queensland:

...access to equipment in some instances is capped at three months but other states have various arrangements. To reinforce what Michael said, it is all over the shop. There is no standardisation: the provision of equipment in some states is insufficient, whilst in others there is no cap.

...Just an example: if you drive around Tweed Heads, outside nearly every second house there is for sale a motor scooter that has been provided by the government or that has been purchased and that they cannot get rid of, yet

11 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 31.

12 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 31.

13 Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 31.

there are all these other people who cannot access these. So it is really very fragmented.¹⁴

10.16 Dr Ken Baker, Chief Executive Officer of National Disability Services (NDS) also explained to the committee that access to equipment and aids in rural areas, due to the scarcity of resources, often requires care providers to take an 'ad hoc' approach when determining what services can be provided:

...in rural services there is often quite an ad hoc approach to constructing whatever package of supports is available from wherever it can be drawn. It is probably not a usual function of HACC to provide this, but in rural areas organisations often have to be very innovative as to how they put together support for people.¹⁵

10.17 Dr Baker also spoke of difficulties of palliative care recipients in group homes accessing equipment under the HACC program in a timely manner:

There has been a longstanding barrier to people in group homes accessing any HACC support whatsoever. There is a commitment in the National Disability Agreement to resolve that barrier and perhaps the National Healthcare Agreement may assist in doing that. This is an example of where there are a range of HACC services that are available to the people in the general community that are not available to people in group homes. The assumption is that people in group homes can get everything they need through the specialist disability service system. It is not true and it disadvantages people with disability.¹⁶

National inconsistencies

10.18 In addition to identifying the need for better access to HACC and HACC-like programs, concerns were consistently raised that patients who do not qualify for HACC are falling through the cracks as the state equipment programs are not adequate.

10.19 Eastern Palliative Care (EPC) explained that the inability of patients, particularly those who do not fall into the aged care criteria, to access HACC services or equipment, is having a negative impact on the quality of care. EPC explained:

Ms Pedley: The difficulty we have for the under-64s is that they do not come under the HACC funding, so they are often denied community based services through local governments.

CHAIR: So they do not qualify for HACC because they do not have a disability—

Ms Moody: That is right.

14 Mr Michael Bishop, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, pp. 32–33.

15 Dr Ken Baker, Chief Executive Officer, National Disability Service, *Committee Hansard*, 24 April 2012, p. 67.

16 Dr Ken Baker, National Disability Service, *Committee Hansard*, 24 April 2012, p. 67.

CHAIR: or they are under 65. Okay.

Ms Moody: That is a real problem with all of the government programs: it is a capsule. If you fall outside that capsule, you miss out on very good support services.¹⁷

10.20 The issue of people under the age of 65 not being able to access HACC services was raised again by the OTA as a major concern:

My concern...is that there are a lot of people on that palliative care or non-curative pathway who do not fall into that aged-care bracket. That is one of the limits. We get a lot of people in their 40s and 50s who do not meet those ACAT criteria or HACC funding criteria. There are a lot of ways that that particular age group falls through many gaps...Certainly in haematology the age groups are huge. I know Olivia's specialty is in adolescent and young adult care. So there is a raft of people and a lot of age groups that just miss out altogether if we just go down the aged-care/ACAT pathway.¹⁸

10.21 Ms Deidre Morgan, an occupational therapist and member of OTA, explained how access to occupational therapy and other services through a HACC like system for younger people is fundamental. Ms Morgan identified that often younger palliative patients do not receive rehabilitation funding as they do not show improvement and therefore separate and additional funding for them is required:

Often rehab funding is based on improvement. If you are not improving then you are discharged. The terminology that is often used is that they have 'failed'. We struggle to get younger people. Yesterday I visited the home of a 39-year-old who nearly fell down the steps while we were there. His goal is to go down the steps every night so that he can lie in bed with his two daughters and read them stories.

...And there is that pressure of funding, so I think we need to be looking at an alternative funding model for rehab for people at the end of life. It is not just cancer; it is the chronic neuros, MND, MS, Parkinson's. These groups of people do not consistently improve and they dip out—they do not access HACC funding.¹⁹

10.22 OTA identified that in these instances, where these younger palliative patients cannot access support services in the community environment, for example through HACC and HACC-like programs, they end up in hospital:

Quite often they will be taking up an acute bed for enormous amounts of time because there is a big black hole there; they cannot be supported in the community with their level of decreased capacity.²⁰

17 Ms Christine Pedley, Manager, Allied Health, Ms Jeanette Moody, Chief Executive Officer, Eastern Palliative Care Association Inc., *Committee Hansard*, 4 July 2012, pp. 6–7.

18 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 22.

19 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 22.

20 Mr Andrew Smith, Registered Occupational Therapist, Leukaemia Foundation, Victorian Palliative Care Special Interest Group, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 22.

10.23 Professor Jane Phillips, a professor of nursing at Notre Dame University and St Vincent's Sacred Heart, also explained the importance of immediate access to HACC or equivalent services – explaining that it is a requirement not only for the patient with the life-limiting illness but also for the carer and/or family who require support:

The thing is that for palliative care there cannot be a waiting list. When we think about HACC services, they are not only for the patient; equally importantly, they are quite often there to support carers to be able to manage. I think one of the things that is not necessarily clearly articulated in a lot of palliative care policy is that people can only stay at home with an invisible network of people supporting them to remain there. That is unpaid carers, augmented with paid carers.²¹

10.24 Professor Phillips also called for the HACC program to be reviewed as a matter of priority given that palliative care recipients will not always be aged care recipients able to access services on account of their age:

Reviewing the way in which HACC is made available to people with palliative care needs is a really important priority. There is great variability, as you have no doubt heard as you have travelled around Australia, in the way in which people can access HACC services. Sometimes for palliative care patients they are not necessarily available, and that may be because an area has exceeded its available funding and there is a waiting list.²²

10.25 Given the evidence it received identifying that different approaches to the administration of equipment and aid programs, the committee sought to understand whether there were national standards and guidelines that applied to the administration of the HACC program:

Senator MOORE: So we have got tomes of guidelines—and they are big; I have seen them, pages and pages—we have the core standard for aged care, and the Commonwealth now has the ownership of HACC. Are there any standards within the HACC Program looking at palliative care?

Ms Balmanno: HACC providers, prior to 1 July and continuing after 1 July, need to comply with the Community Care Common Standards, which are the same standards that are applied to community care providers under the Aged Care Act—so for package care providers.

Senator MOORE: So it is a standard two lines in terms of the standard, and then the big guidelines.

Ms Balmanno: The standards themselves are quite short. The review process against the standards, in terms of what is considered in assessing compliance with the standards and whether people are meeting the standards, is much more involved, which is causing us some challenges with the transfer of HACC providers to the Commonwealth, because

21 Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, p. 60.

22 Professor Jane Phillips, *Committee Hansard*, 2 July 2012, p. 60.

obviously some of them are quite small services through to quite big services who would be performing palliative care-type arrangements in the community and things like that. We also have the very small Meals on Wheels team and others who are operating in a different way. But it is the same standards that apply.²³

Is there a better approach?

Is better regulation required?

10.26 When providing evidence to the committee, OTA explained that community service providers and district nurses no longer own equipment due to the storage problems and maintenance costs. However as the hospitals hold the equipment it is they that now grapple with these issues, but generally handle them differently.²⁴

10.27 OTA also commented on a new problem – the incorrect prescription of equipment – and the importance of prescribing the appropriate equipment:

...you do not want to prescribe something that is going to make somebody more dependent and more physically unable to care for themselves and be at home for as long as possible.²⁵

10.28 OTA informed the committee of instances in which case a person who has had their drivers' license revoked can purchase a motorised scooter:

You can go into an equipment shop and buy a scooter, which is another dodgy issue when you have had your car licence taken away... Somebody can have their licence removed, because they are unsafe to drive because they have a visual defect with hemiparesis, and go to a shop that sells medical health equipment—and they are popping up everywhere—and be sold a scooter for several thousand dollars and pop off down the road with a little orange flag. I know there has been at least one death or even two deaths while crossing four-lane roads.²⁶

An equipment library?

10.29 In the course of the committee's inquiry, reference was made to the Motor Neurone Disease (MND) equipment library that operates in Victoria. The committee sought more information in relation to this program:

MND is obviously a relatively small diagnostic group and it has a relatively predictable and enormous decline in function from walking to only being able to... It has an enormous functional decline that is very predictable. The MND Society has, through fundraising over many years, created an

23 Ms Rachel Balmanno, Acting First Assistant Commissioner, Ageing and Aged Care Division, Department of Health and Ageing, *Committee Hansard*, p. 39.

24 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

25 Mr Andrew Smith, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

26 Ms Deidre Morgan, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

enormous equipment library with things like hoists, hospital beds, air mattresses, wheelchairs.²⁷

10.30 The committee heard that the main benefit of the MND library was the speed in which people could access equipment:

One of the main points about the MND library is that it is usually very quick to access these things, so you are not waiting like you are with the main equipment provider, which is SWEP. You can be on a waiting list for 18 months, which is not much use for someone who might be dead in 12 months.²⁸

10.31 The committee understood that the MND library was established to overcome delays patients had been experienced when accessing aids and equipment through the state government run programs.

Committee comment

10.32 The committee is concerned that support and treatment for people with a life-limiting illness during the later stages of their disease may be difficult to access, and is also concerned by the inconsistency across jurisdictions in relation to accessing aids and equipment. The committee was impressed however by the MND Equipment Library and, while the committee acknowledges that not all life-limiting illnesses have the same predictability in the decline of a patient's function, it considers that the implementation of an equipment library on a national basis should be considered. A national 'equipment library' may limit delays in both accessing equipment and having equipment collected or removed following the passing of a palliative care patient.

10.33 The committee notes that since 1 July 2012 the Commonwealth HACC Program is providing funding for basic community care services which support frail older people and their carers. Those eligible include people aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people); and those at risk of premature or inappropriate admission to long term residential care, or a carer of older Australians eligible for services under the Commonwealth HACC Program. While it is too soon to tell whether those changes will be effective, the committee takes the view that the implementation of those changes should be closely monitored to ensure that the issues which were identified during the course of the committee's inquiry are addressed. To ensure that younger people requiring HACC-equivalent services and equipment do not fall through the gaps, the committee would like to see the state and territory governments, through COAG, look at establishing a consistent approach to the provision of equipment and services for those younger people. Alternatively, the government could consider including 'palliative care' as an eligibility criteria for access to the HACC program – ie a person with a life limiting illness would qualify for HACC services and equipment regardless of age.

10.34 The committee was also troubled to hear of the incorrect prescribing of equipment. Although it did not receive much evidence on this particular point, the

27 Mr Andrew Smith, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

28 Mr Andrew Smith, Occupational Therapy Australia, *Committee Hansard*, 4 July 2012, p. 24.

committee suggests that the government examine this issue and whether current regulatory structures and prescribing guidelines are sufficient to address these concerns.

Recommendation 20

10.35 The committee recommends that the Council of Australian Governments examine the viability of introducing a national equipment library for palliative care patient needs, examining whether such an approach would allow more efficient and timely provision of available equipment and funds.

Recommendation 21

10.36 To prevent the mis-prescribing of equipment, the committee recommends that the Australian government investigate current regulation and consider improving regulation of both private and public palliative care equipment providers.

Recommendation 22

10.37 The committee recommends that the Australian government closely monitor implementation of the recent changes to the Home and Community Care program to ensure that the program is meeting the needs of those over 65, and that palliative care recipients who do not fall into the aged care bracket are receiving adequate support.

Recommendation 23

10.38 The committee recommends that the Australian government consider changing the eligibility to Home and Community Care (HACC) to include palliative care patients or carers of such patients, regardless of their age. The committee notes that as the HACC program is linked to funding and funding agreements, the Australian government consider this recommendation in the context of considering changes to the funding model for palliative care.

Recommendation 24

10.39 The committee recommends that the Australian government analyse and identify potential gaps in the provision of palliative care and palliative care funding for people with disabilities, especially in supported accommodation.

