Flinders University | Research Centre for Palliative Care, Death & Dying

Optimising for Use

Enhancing the Efficacy of the CarerHelp Information Kit

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About the Flinders Research Centre for Palliative Care, Death and Dying

The Research Centre for Palliative Care, Death and Dying (RePaDD) is hosted by the College of Nursing and Health Sciences at Flinders University.

The Centre's mission is to make a difference to palliative and end-of-life care by examining issues and challenges experienced by people living with a life-limiting illness, their families and carers, and health and care professionals supporting them.

RePaDD comprises of a multidisciplinary research team with a diverse set of skills and experience in working in a variety of settings. The group has an extensive track record in delivering successful national palliative care projects as well as high impact research and evaluation relating to palliative care, community experience of death and dying, innovative models of palliative care, and the contribution of palliative care to individuals at the end of life, health professionals and health and social care systems.

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Executive summary

This report presents findings from a mixed-methods study examining how a printed version of the CarerHelp Information Kit is accessed, distributed, and used by Specialist Palliative Care Services (SPCS) and local councils, as well as how carers experience and engage with the resource. The Kit comprises factsheets and practical pointers and is designed to support a person providing care to someone living with a life limiting illness. It helps carers orient themselves to different aspects of caring, respond to needs associated with advancing illness, and manage grief and bereavement. The study was designed to assess the feasibility of different distribution pathways, explore how carer information is introduced and used in practice, and identify opportunities to optimise the effectiveness of printed carer resources across health and community settings.

A targeted email campaign was used to promote the availability of the printed kit, with engagement and conversion tracked through a dedicated landing page. Over half of contacted organisations engaged with the campaign, and nearly one-quarter of those who visited the landing page placed an order, indicating that such an approach is feasible. Conversion was consistently higher among specialist palliative care services than local councils, reflecting differences in carer identification, organisational purpose, and perceived immediacy of relevance. Orders were received from a wide range of geographic locations and service types, suggesting broad interest in printed carer resources across both health and community contexts.

Follow-up contact and interviews with service providers, council staff, and carers suggested that the CarerHelp Information Kit was widely regarded as a credible and valuable resource. However, its perceived usefulness and impact were strongly shaped by how, when, and by whom it was introduced. Providing the full kit at once was often viewed as inappropriate, particularly when carers were experiencing high levels of stress or information overload. Instead, selective and staged provision supported by professional judgement and contextual framing was viewed as more effective in helping carers engage with and use the information.

Across the interviews, carers' information needs were described as dynamic and situational, changing over time and intensifying at key transition points rather than following a single predictable trajectory. While carers sometimes expressed differing views about whether information should be provided early or introduced progressively, these perspectives reflected varying needs and underscored the importance of clear signposting and navigation aids that enable carers to quickly identify what information is most relevant to them at a given point in time.

The findings also highlight the central role of human mediation in effective information provision. It was clear that SPCS play a critical role in identifying carers, endorsing resources, prioritising content, and helping carers interpret information in ways that aligned with their circumstances. In contrast, carers are often identified indirectly in community settings and do not always self-identify as 'carers', limiting engagement with carer-labelled resources and reinforcing the importance of potentially effective, trusted intermediaries such as councils, libraries, and community organisations.

Taken together, the findings suggest that the effectiveness of the CarerHelp Information Kit depends not only on the quality of its content, but on clarity of purpose, timing and method of delivery, and alignment with carers' individual circumstances. The findings point to an opportunity for CarerHelp to enhance the efficacy of the kit by reconceptualising it as a modular, staged resource, strengthening guidance for services and councils on when and how to introduce information, and mapping and leveraging key points of intersection across health and community settings to ensure that carer information supports carers when it is most needed.

Opportunities for CarerHelp

1. **Reconceptualise the CarerHelp Information Kit as a modular, staged resource rather than a single comprehensive package**

   Because carers' information needs change over time and are most acute at key transition points, providing the full kit at once risks information overload – particularly when carers are under stress. CarerHelp could consider whether a modular design, with resources aligned to different stages of the caring journey (e.g. early diagnosis, increasing care intensity, end of life care) would be valuable in enabling use and uptake.

2. **Strengthen guidance for health services and councils on when and how to introduce CarerHelp resources**

   Findings suggest effective use of the content is enhanced by support and guidance from the people who are providing the resource. This support focus reflects the context reality of being a carer for someone who is seriously ill where death is an expected outcome. Developing simple, practical guidance for service providers and council staff to support selective, staged provision, including prompts for timing, prioritisation, and framing of information may support the introduction of CarerHelp resources.

3. **Expand and formalise distribution through trusted community touchpoints beyond specialist services**

   While SPCS play a key role, the study identifies councils, libraries, primary care, respite services, and other community-based settings as potentially viable access points for some levels of information provision and direction to supports. Community access points may be particularly helpful to people providing care who not connected to specialist services or who do not self-identify as carers. Strengthening partnerships and distribution pathways through such trusted touchpoints, could support early identification and engagement by carers.

4. **Review language and framing to better reflect diverse caring identities and relationships**

   Many people providing substantial care do not identify as 'carers', limiting engagement with carer labelled resources. Broadening language and presentation will help people who see themselves as partners, family members, friends, or neighbours to see value in these resources.

5. **Design resources with explicit recognition of carer stress, cognitive load, and information overwhelm**

   The study shows that carers' ability to absorb and use information is often constrained by stress, fatigue, and competing demands. Simplifying, signposting, and prioritising resources, including highlighting what is most important 'right now', and ensuring critical practical information (e.g. emergency contacts, next steps) is easy to locate will help support carers.

6. **Position the CarerHelp Information Kit as part of a broader system of supported care rather than a standalone resource**

   Evidence from the study underscores that the kit is less effective without mediation, context, and connection to services. While emphasising the role of human support, informal networks, and service navigation, CarerHelp could explore ways to better integrate its resources with related programs/initiatives across the carer landscape.

Background and introduction

Most people living with a terminal illness and approaching death will need the assistance of a non-professional carer such as a family member, friend, or neighbour to provide physical, emotional, and practical support. Many of these carers can feel overwhelmed, isolated and experience psychological and/or financial distress. Carers may also have unmet information needs, and these needs can change over time.

CarerHelp provides free, trustworthy information, tools and support for people caring for someone with an advanced illness or nearing the end of life, helping carers understand what to expect, access services, communicate effectively, and care for their own wellbeing.

While data shows that the CarerHelp website is being accessed, the needs of carers can be extensive.[1] Research also shows that carers can struggle to search for and find relevant information and that carers can benefit from information that is printed and/or brokered by health professionals and other trusted parties.[2] Users of online health information want recognisable, trusted sources and preferred resources created in multiple formats. However, users also acknowledge the various print formats in which older adults prefer to access health information, which includes magazines, pamphlets, and books.[3]

Beyond providing resources, services have a key role in facilitating information at critical points and working in a responsive and effective way with the unpaid carer. Studies with caregivers of people living with dementia note that the caregivers have a strong expectation that the primary care providers should recommend, endorse, and guide them to specific sources of care and information, which can include referrals to other healthcare professionals, print material, and community and internet resources. This highlights the importance of health professionals having access to trustworthy information that can be shared or recommended.[4] Carers also use multiple avenues (people, venues, and formats) to seek health information; the process is dynamic and multifaceted. The role of local government has also been seen as a potentially beneficial route.[5] Libraries have also been identified as a valuable source of health information.[6,7]

In view of the above, this study sought to understand the role that printed materials – and the CarerHelp Information Kit in particular – which are recommended and/or provided by health professionals can play in the supports provided to unpaid carers. It also seeks to understand how health services and community services can broker resources to carers and incorporate the provision of carer information in their organisational practices.

Because the value of printed resources depends not only on perceived usefulness but also on whether services and community organisations engage with distribution pathways in practice, the study combined engagement and uptake tracking with follow-up feedback and interviews with specialist palliative care services (SPCS), local councils and carers.

Study methodology

Project overview

This study employed a mixed methods approach to examine how SPCS nationally and South Australian (SA) local councils access, use and disseminate a printed version of the CarerHelp Information Kit, and better understand carers' experiences with the resource. It combined engagement tracking and kit uptake following a targeted promotional activity with follow-up feedback (including interviews) to gauge feasibility of distribution pathways and examine the conditions that shape effective use. The CarerHelp Project is funded by the Department of Health, Disability and Ageing with the aim of providing resources for carers caring for someone

with palliative care needs and/or coming to the end of their life.[8,9] The core analytical focus was on identifying what information matters to carers, when it matters, and who is best placed to provide it, with particular attention to how information provision is shaped by context, timing, and service interactions.

The study targeted two key service settings involved in carer support: SPCS and South Australian local councils. Additionally, interviews were conducted with carers who had used the CarerHelp Information Kit. Together, these perspectives enabled examination of Kit use across health, community, and lived-experience contexts.

The objectives of the study were:

1. To track usage patterns of the CarerHelp Information Kit for two targeted groups: Special Palliative Care Services (SPCS) and South Australian Local Councils
2. To investigate how SPCS incorporate this palliative care resource for carers into their service work processes
3. To document how local councils identify those with carer responsibilities and make the resources available within their communities
4. To explore the value of print resources
5. To seek carer feedback on the resources through SPCS and local councils

Ethics approval was received through Flinders University (HREC 8698).

Engagement and recruitment

Engagement and recruitment occurred in two linked phases. These were designed to examine SPCS and council engagement with the promotional activity and landing page ordering pathway, how ordered kits were used, as well as invite feedback (including interviews) from services, councils and carers.

Phase 1 involved contacting SPCS and SA local councils to alert them to the availability of a printed version of the CarerHelp Information Kit. To order kits (a maximum of 5, free of charge), services and councils were directed to a purpose-built landing page (Appendix 1) and asked to provide basic information to enable delivery and agree to receive a follow up contact on whether the resources were used. As part of this process, participants were asked to provide feedback regarding their motivation for ordering the kits and how they intended to use them during the process of ordering (Appendix 1).

Phase 2 involved follow-up telephone contact with services and councils that had ordered kits (4 weeks after dispatch). This served to confirm receipt of the kits, better understand how and whether the resources were distributed or intended to be used, explore perceived usefulness and implementation considerations, and invite further feedback on the resources (Appendix 2). As part of this process, those who had ordered kits were also provided with study information that could be shared with carers, inviting participation in an interview. (Appendix 3).

Prospective participants from SPCS and SA local councils were recruited via telephone when follow up contact was made, and/or during direct discussions with local councils and/or SPCS as a result of referrals or organic contact with such organisations. Both of the carers who were interviewed were recruited via organic contact at an SA local council event in which CarerHelp participated via promotional kit promotional activities. Individuals who agreed to be interviewed

were sent a Participant Information and Consent Form (Appendix 4 and 5) and an interview time scheduled. Carers who participated were provided with a $50 Gift Card.

Data collection and analysis

Data were collected through a variety of mechanisms as part of a mixed methods design to examine (1) service and council engagement with the promotional activity (2) reach and uptake of the printed CarerHelp Information Kit and (3) how the Kit was used and experienced in practice. Data collection methods included:

- Engagement and uptake tracking associated with the promotional email and landing page (including response and engagement indicators, and kit ordering)
- Information captured at the point of kit request (e.g. organisation-type, staff role, location, number of kits requested, intended use)
- Follow-up feedback gathered through telephone contact; and
- Semi-structured interviews with SPCS, council staff, and carers.

Audience engagement and traffic source attribution were enabled through the use of Google Campaign URL Builder, which generated unique Urchin Tracking Module (UTM)-tagged URLs for each audience group (SPCS and Councils) included in the email campaign. UTM parameters allowed Google Analytics 4 (GA4) to distinguish traffic originating from each audience segment and measure landing page visits and engagement events separately for SPCS and Councils

Order data was collected from the server web forms, securely stored in the database, and analysed via the CarerHelp Kit Orders CSV, providing verified counts of orders by organisation-type (SPCS vs Council).

Semi-structured interviews allowed participants to describe their perspectives and experiences in their own words while ensuring coverage of key topics related to information and kit provision, use, and support. Interview guides (Appendices 6, 7 and 8) were tailored to each participant group (SPCS, council staff, carers) and focused on carer identification, information needs over time, distribution practices, and perceptions of the CarerHelp Information Kit. Interviews took place via telephone or MS Teams and averaged around 45minutes.

Quantitative and descriptive uptake data captured at the point of kit request were analysed using simple descriptive analysis, with frequencies and proportions reported. Responses from follow-up phone calls and emails were recorded in an Excel spreadsheet and summarised descriptively to capture feedback on kit receipt and use. Interview data from SPCS and local council representatives were analysed using content analysis [10], and carer interview data were analysed thematically.[11] Guided by the study's objectives, all of the data collected was analysed, synthesised and organised into the key findings presented in this report.

Key Findings

Engagement and conversion

A targeted email campaign was undertaken to promote engagement with the kit via the CarerHelp landing page, with engagement and conversion tracked across SPCS and councils. Of the 309 people/organisations that were emailed, 164 (53.25%) visited the landing page. From these visits, a total of 38 orders were received, representing a visit-to-order conversion rate of 24%.

Of the 240 emails sent through to SPCS, 140 landing page visits were recorded and a total of 32 orders placed. Of the 69 emails sent through to councils. 24 landing page visits were recorded and 6 orders placed.

While levels of engagement (defined as landing page visits plus other recorded contacts) were comparable for both SPCS (59.17%) and Councils (53.62%) (with slightly higher engagement among the SPCS audience), it was clear that conversion was consistently higher among SPCS (see Table 1).

Table 1. Conversion rates: SPCS and councils

Conversion Stage	SPCS	Councils
Email → Engagement	59.17%	53.62%
Email → Order	13.33%	8.70%
Engagement → Order	22.54%	16.22%

Overall, the campaign achieved moderate to strong engagement, with over half of the organisations contacted visiting the landing page and nearly one-quarter of engaged organisations placing an order, suggesting that a low-cost, email-based distribution model is potentially feasible across both specialist and community settings. However, higher conversion among specialist palliative care services suggests that scalability is strongest where carer identification and resource relevance are already embedded, suggesting the importance of tailored strategies and implementation support when extending distribution into broader community contexts.

Access and ordering

To better understand kit distribution pathways, access, ordering, and usage patterns, data were collected at the point of kit request. This information included organisation-type (SPCS or council), staff role, geographic location, number of kits ordered, reasons for requesting the kits, and how respondents anticipated the kits would be used (Appendix 1). In addition to describing ordering characteristics, these uptake indicators provide a practical measure of feasibility by indicating the extent to which targeted services and councils engaged with the distribution pathway following the promotional activity.

Reach, organisation, role and location

Two hundred and forty SPCS Australia-wide and all of South Australia's 69 local councils were contacted via email. Specialist services were identified through the development of a contact list, while SA councils were contacted using publicly available email addresses. Orders were predominantly placed by SPCS (n=32, 84%), with Councils also represented (n=6, 16%). Kits were requested from Victoria (n=12), South Australia (n=7), New South Wales (n=7),

Queensland (n=6), Western Australia (n=4) and Tasmania (n=2), with orders distributed across metropolitan, regional, and outer-metropolitan areas, indicating broad geographic reach.

Requests for the CarerHelp Information Kit were received from a range of organisation types, reflecting both health and community-based service contexts. Orders were most commonly placed by staff in client-facing or coordination roles (e.g. clinical nurse consultants, social workers, nurse unit managers, service managers), suggesting that kit requests were closely linked to direct engagement with carers. This distribution supports the relevance of printed resources across diverse service and community contexts.

Number of kits ordered

During the kit promotion period (July-December 2025), a total of 181 kits were ordered, with 30 kits (17%) requested by SA local councils and the remainder (151, 18%) ordered by SPCS. The overwhelming majority of those who ordered kits (92%) availed themselves of the 5-kit maximum.

Reasons for ordering and intended use

When surveyed via the landing page, respondents reported ordering the kits for a range of different reasons. Among SPCS, 55% of those who provided feedback on what prompted them to order resources nominated 'We saw your email and thought they would be useful in our service'. This was followed by 'We know there is a need for carer resources' (33%) and 'We know about CarerHelp' (13%). Among councils, 5 respondents (45%) nominated 'We saw your email and thought it looked relevant', 4 respondents (36%) nominated 'We know of residents who could benefit from these resources', and 2 respondents (18%) nominated 'We have staff who could benefit from these resources'.

Similarly, respondents reported a variety of ways in which they intended to use the resources. Among SPCS, 28% nominated 'Members of the team will make them available if carers are seeking more information', This was followed by 'We will share them with others in our team to help them become aware of carer resources' (25%), 'We will share them during scheduled appointments' (18%), 'We will add it to our pack for all new patients and their families' (16%), and 'We will use them at carer sessions or events' (13%).

Among councils, 5 respondents (50%) nominated 'Council staff may make these resources available to residents', 3 respondents (30%) nominated 'This resource will be of interest to our council staff', and 2 respondents (20%) nominated 'We have some council health and aged care services'.

These findings suggest that CarerHelp resources are most often ordered in response to perceived usefulness and immediate relevance, rather than through established or systematic pathways, highlighting the importance of visibility, timing, and professional judgement in activating uptake.

Telephone follow-up with services and councils

Telephone follow-up contact was made with organisations that ordered the kit to confirm receipt, identify any delivery issues, and document early indications of local use and perceived usefulness.

Of the 38 organisations that placed orders, most contacts who were reached confirmed that kits had arrived (27/38). Delivery issues were uncommon in the data recorded, with a small number of instances noting phone connection faults or the need to verify contact details;

however, the follow-up process itself was often constrained by limited availability and difficulty reaching the nominated contact (e.g. repeated non-response and out-of-office messages recorded across multiple services).

Where feedback was obtained, initial perceptions of the kit were consistently positive, with the kit commonly described as 'useful', 'helpful', or potentially so. Early use was variable and typically modest at the time of follow-up, with some sites reporting that several kits had already been distributed directly to carers (often one or two kits) and others indicating planned distribution following internal review or team briefing. When distribution had occurred, it was most commonly enacted through direct handover to carers during service contact, with additional dissemination approaches including making kits available on request, placing resources in waiting rooms or community access points, and sharing via council/community settings (e.g. reception desks, community centres, libraries, and events).

Willingness to be involved in the study further was mixed, with some contacts indicating openness to a short interview (often framed as occurring in coming weeks). It was also clear that most of those with whom contact was able to be made had not yet discussed study participation with carers. Overall, the follow-up calls functioned as a useful check on delivery and early implementation, suggesting that while the kit was well regarded, uptake and distribution practices depended on local workflows, staff capacity, and the availability of appropriate opportunities to identify and engage carers.

Health service, council and carer interviews

In addition to the findings presented above, a total of eight people were interviewed. Four were from healthcare settings and all of these participants were social workers. Three of the four interviewees were employed within SPCS, with two based in Queensland and one in Victoria. The remaining participant worked in a Geriatric Evaluation and Management (GEM) Unit in South Australia. Two participants were interviewed from local government settings, both of whom were employed by Onkaparinga Council in South Australia. One participant held a library coordinator role, while the other was a social wellbeing coordinator. Two carers were interviewed, both of whom were located in South Australia and caring for a family member with Dementia.

Findings from the interview component of the study are presented thematically across health services, local councils, and carers, reflecting shared and intersecting experiences rather than discrete, setting-based accounts. This cross-cutting approach supports the identification of common processes and challenges, as well as factors that enable or constrain how carers are identified, supported, and engage with information and services across the care journey. Presenting the findings in this way highlights the complex, situational, and relational nature of caring, and the extent to which carers' needs evolve over time in response to changing circumstances and service interactions.

1. Referral, carer identification, and early engagement with support

Across the interviews, referral pathways and processes for identifying carers were described as uneven and context-dependent. Participants from health services noted that patients were referred to palliative care at different stages of illness and across a wide age range, resulting in significant variation in both patient and carer needs. As one participant observed:

> We definitely do get patients where they're quite early…in terms of their palliative care journey. But then we do often get patients as well where they're much more unwell and their disease has progressed a lot more and they need a lot more support.

While carers were recognised as a critical 'link' between patients and services, they were not always the explicit focus of attention early in the care journey. Health service participants described how, at initial referral, clinical priorities often centred on the patient, particularly where the perceived burden on carers appeared relatively low. As one interviewee explained:

> Often they'll [carers] be the link, particularly if it's the partner or a son or daughter or somebody actually living with the person.

However, as illness progressed and care needs intensified, the burden on carers often increased rapidly, prompting a shift toward more active identification of carer needs. One participant observed that:

> …at that early stage, because a lot of our referrals are [in the] stable phase, often there isn't a huge amount of burden on the carer at that point in time. As things…start to deteriorate and the person becomes more unwell…the burden increases on the carer…[and] you start to see them need those extra supports.

This meant that opportunities for early, proactive engagement with carers were sometimes missed, despite carers' central role in coordinating care, managing appointments, and day-to-day support.

Council participants described similar challenges in identifying carers early (within the community), particularly where individuals did not self-identify or where caring occurred informally (e.g. neighbours). Identification often occurred indirectly and was embedded within broader service interactions such as myaged*care* assessments, engagement with Commonwealth Home Support Program services, or contact through Positive Ageing Centres. These indirect pathways of identification reflected the reality that caring roles frequently emerge gradually and are not always immediately recognised as such by those providing care.

2. Carer identity, complexity, and situational context

A consistent and prominent finding across all participant groups was that many people providing care did not identify themselves as 'carers'. Carer identity was described as situational, relational, and fluid, influenced by existing family roles, social relationships, and the gradual accumulation of caring responsibilities. Health service participants noted that carers 'probably wouldn't consider themselves a carer in a lot of circumstances', particularly in the early stages of care when they may still be working or managing other aspects of daily life.

Carers themselves expressed ambivalence and (some) discomfort with the term. One carer contrasted paid caring with unpaid family care, explaining that:

> When I think of a carer, I think of someone who is paid to do a job and [has] a start and stop point. When you're a parent, it's 24/7…when someone says 'oh, you're a carer', to me it sounds weird.

Council participants reinforced these observations, noting that caring often occurred within broader social relationships and informal arrangements. One council staff member explained that carers 'don't always identify themselves as carers', and that increasing staff and volunteer awareness was critical to recognising people in caring roles who 'don't see themselves in a formal caring role'.

This contrast highlights an important difference between SPCS and community settings. Within SPCS, carers are readily identifiable due to their link to the person receiving palliative care. In community settings, however, caring roles are often more diffuse and less visible, underscoring the importance of building awareness and recognition of carers among community providers.

Across settings, caring was understood to occur within highly complex and diverse personal contexts. Participants emphasised that carers' circumstances varied widely, from individuals with minimal social or financial support to those embedded within extensive family and community networks. As one health service participant noted, carers' situations could range:

> From people with zilch to somebody who's just really fortunate there's somebody down the street that has kind of adopted them and helps out in emergencies, to people that are really fortunate and maybe have a really, really wide network of people. It really does vary.

Indeed, carers may have known the person for whom they were caring 'for many, many years', or only 'for a very short time', further complicating assumptions about capacity, knowledge, and support needs.

This complexity limited the extent to which carers' needs or circumstances could be assumed and reinforced the importance of flexible, individualised approaches to identification and support. Participants consistently emphasised that caring contexts were both layered and dynamic.

3. Support needs and direct assistance across the care journey

Carers were described as having a wide range of interrelated support needs – from emotional and practical to informational and decision-making. Participants across settings emphasised the importance of emotional support, including opportunities for carers to talk through their experiences and concerns. Health service staff noted that carers often sought separate conversations, particularly when discussing sensitive topics or when patients were distressed by such discussions. One participant, for example, described carers asking: 'Can you tell me a little bit about what do I do if they die at home?'.

Noteworthy here is that direct and practical assistance from service personnel was frequently described as critical due to the limitations of information provision. When carers were experiencing high levels of stress or overwhelm, written information alone was often deemed insufficient because:

> When people are super overwhelmed, it's really hard for them to take in information.
>
> There's often other things going on in their lives and they're really overwhelmed and not at all across that information and definitely need more guidance and probably some ongoing follow-up from our team.

In such circumstances, hands-on assistance – such as sitting with carers to complete tasks, navigate systems, or plan next steps – was viewed as essential. As one participant noted:

> When you do have carers who are super overwhelmed…and things aren't getting done because they're so overwhelmed, I think it is easier just to go in and sit with them and do it practically with them.

Similarly, council participants emphasised the need for support that extended beyond information, including respite services, social connection, and navigation assistance. Programs such as flexible respite, friendship clubs, and Positive Ageing Centres were described as important mechanisms for supporting carers' wellbeing and capacity to continue caring. Carers' own accounts reinforced these observations, describing the cumulative burden of practical, logistical, financial, and legal challenges, often managed alongside paid employment and other family responsibilities.

4. Barriers to access: awareness, overwhelm, digital limits, and system navigation

Barriers to accessing support were described as cumulative and reinforcing, rather than isolated or singular. Across the interviews, participants highlighted limited awareness of available services, information overload following diagnosis or referral, and difficulties navigating complex health and aged care systems. Health service staff, for example, described situations in which carers were provided with large volumes of written material that went unused:

> I used to turn up at home visits for people who'd just been diagnosed with cancer and they'd have a shopping bag full of paperwork…most of them would say, 'It's too much…so I just put it in the wardrobe and I haven't looked at it again'.

Council participants echoed these concerns, noting that carers frequently expressed surprise at the existence of services (e.g. 'I didn't even know this existed'). Navigating the aged care and other complex systems was described as particularly challenging for vulnerable individuals and carers without family support. One council participant observed that navigating the system:

> …can be quite complex, particularly for people that don't have any family connections…or anyone that can help them navigate through the system and get the supports that they need.

Over-reliance on digital information was also identified as a barrier. Council participants noted that distributing information digitally did not always reach those most in need, particularly carers without reliable access to, or confidence with, digital technologies. This finding in particular reinforces the critical role that councils, libraries and community groups can play as trusted brokers and intermediaries of key information, particularly for carers who may not access or engage with digital resources.

Together, these intersecting barriers – lack of awareness, information overload, digital literacy, and system complexity – constrained carers' capacity to identify, access, and use all of the support that was potentially available to them.

5. Information needs over time and informal sources of support

Information needs were consistently described as dynamic and changing over time, rather than static. Carers and service providers emphasised how different stages of the caring journey required different types and amounts of information, and that information provided too early, or without adequate framing, could feel overwhelming. One carer reflected on how, while the information was valuable, at times they were 'only wanting to really do step one', highlighting the importance of staging and prioritisation.

Informal and organic sources of information were described as particularly valuable. Carers in particular spoke of learning about services, entitlements, and practical strategies through peer networks, community groups, and everyday conversations. One carer described how attending a dementia group enabled informal exchanges such as, ‘Have you applied for [this or that] package?’ or learning about supports like the Companion Card. These interactions were viewed as timely, accessible, and closely aligned with carers’ needs at a given point in time.

Human connection was central to these processes, with carers emphasising the value of speaking with others who had navigated similar experiences, and noting that such interactions helped reduce isolation, build confidence, and make sense of complex information.

6. The CarerHelp Information Kit: value, limits, and conditions for effectiveness

The CarerHelp Information Kit was consistently viewed as a valuable and credible resource across health services, councils, and carers. Health service participants praised the quality and relevance of the content, describing the kit as a ‘key resource’ and noting that carers ‘have loved the medication sheets’. The design and structure of the kit were also praised, with information organised into clear sections corresponding to different stages of palliative and end-of-life care.

However, the effectiveness of the kit was tied closely to timing, staging, and mediation by trusted individuals. Participants across settings emphasised the importance of selective and bespoke provision, rather than distributing the full kit at once. Health service staff described providing different sections at different times to avoid information overload, while carers noted that the kit would have been most helpful if received earlier in the caring journey:

> It [the kit] was great. I liked all the information that you had…[but it would have been better] if I had got that package at the beginning.

Suggested improvements focused on clearer navigation and signposting (e.g. contents page), staged access to information, and prominent practical details such as emergency contact information. It should be note that concerns about overwhelm were not framed as dissatisfaction with the content itself, but as a reflection of carers’ limited cognitive and emotional capacity to absorb such content during periods of difficulty and stress.

7. Human judgement and mediation as the enabling mechanism

Across all of the participant groups, human judgement and mediation were identified as central enabling mechanisms for effective support. Whether through health professionals, council staff, or trusted community contacts, endorsement, explanation, and guidance helped carers prioritise information, understand its relevance, and apply it in practice. For example, health service staff described informal ‘car door conversations’ as valuable opportunities for carers to ask questions ‘out of earshot’ of patients, while council staff highlighted the importance of providing resources within existing relationships and service interactions (e.g. council libraries).

These findings underscore that the impact of information resources depends not only on content quality, but on how, when, and by whom information is introduced and supported. Human mediation was critical in ensuring that information and resources were usable in view of the realities of carers’ lived experiences, particularly in the context of stress, fatigue, complexity, and individual circumstances.

Key learnings and implications for CarerHelp

How the Carerhelp Information Kit is used in practice

This study aimed to understand how the CarerHelp Information Kit is actually used by services and carers, assess the feasibility of selected distribution pathways and examine the conditions that shape effective use. The findings highlight the potential of distribution through SPCS and councils, as well as the limits of unmediated provision. The findings also demonstrate that use of the kit does not follow a linear or uniform pathway. Instead, use is shaped by complexity of carer circumstances, the timing of information provision, and the presence – or absence – of human service providers. Across services, councils, and carers themselves, the kit functions less not as a standalone resource; but as a component within broader systems of support and decision-making.

For services, particularly SPCS, the kit tends to be used selectively and purposively. Rather than being provided wholesale, elements of the kit are often embedded within existing conversations at key points of transition, uncertainty, or need. This approach – already utilised in practice by many of those interviewed from SPCS – appears to support more meaningful engagement by carers, as information is contextualised and framed by trusted professionals who can interpret, prioritise, and guide its use.

Councils, in contrast, often operate as a generic and accessible interface for carers and community members. This positions them as a logical distribution point for CarerHelp resources, particularly for people not connected to specialist services. However, in view of the complexity of carer circumstances and consequent need for mediation by human service providers, the findings suggest that distribution alone is insufficient. Effective use depends on councils being able to frame the resource, provide basic guidance, and link carers to appropriate supports; functions that require capacity and confidence among council personnel.

From the perspective of carers, the usefulness of the kit is tied closely to when it is received and how it is supported. Carers consistently described the value of receiving information early, particularly at the beginning of the caring journey or at key transition points. Information provided too late, or without adequate framing, risked overwhelm or underutilisation, regardless of quality or relevance.

Complexity and changing information needs over time

A central finding of the study is that navigating the care journey is not a linear process. Carers' needs, capacities, and identities evolve over time, often in response to changing health status, escalating care demands, and shifting personal relationships. As a result, the value of information is largely dependent on when it is provided, how it is introduced, and whether carers are supported to engage with it.

Indeed, the findings highlight that carers' information needs are most acute at points of transition or uncertainty – such as diagnosis, when approaching the end of life, or during bereavement – rather than at a single, predictable moment (e.g. upon referral to palliative care). Such findings suggest that a one-off, comprehensive information kit may not be able to meet carers' needs throughout the care journey; instead suggesting the need for a more flexible, staged approach that acknowledges evolving changing carer needs.

Noteworthy here is that the complexity experienced by carers is not only informational but also situational and emotional. Carers described significant cognitive, emotional, and practical overload, which directly affected their ability to absorb and act on information. Under these conditions, the mere availability of high-quality information is insufficient; information must be

provided in ways that are accessible, prioritised, and usable in the context of carer stress and fatigue.

Implications of Carer Identity and Language

The findings also underscore the importance of recognising that many people providing care do not identify as ‘carers’. This lack of self-identification has significant implications for the reach and utility of the kit, and CarerHelp resources more broadly. Resources explicitly framed for ‘carers’ may not resonate with, or be utilised by, individuals who see themselves primarily as partners, children, friends, or neighbours rather than carers.

This knowledge contains implications both for both language and engagement. For services and councils, there is a clear need to increase awareness among staff and volunteers to help identify people in caring roles, even when individuals themselves do not use the term. More broadly, it suggests that CarerHelp may need to adopt more inclusive framing that reflects the diversity of caring relationships and identities, without relying solely on formal labels.

Distribution Points and the Role of Human Mediation

In addition to the above, the study highlights the importance of distribution points that are embedded within carers’ everyday interactions and trusted relationships. In addition to councils and specialist services, participants identified respite services, libraries, GPs, and community-based programs as valuable nodes for identifying carers and providing information. Particularly noteworthy in this respect is that respite settings could act as particularly effective environments for information provision, as carers were often operating under reduced cognitive and emotional strain, enabling greater capacity to effectively engage with resources.

Across settings, the presence of a human interface also emerged as a critical factor in supporting effective use of the kit. Endorsement, explanation, and guidance from trusted professionals or staff helped carers to prioritise information, understand its relevance, and feel supported in using it, reinforcing the idea that in order to maximise its impact, the kit should be viewed – and provided – as part of an interactive process.

Implications and opportunities for CarerHelp

For CarerHelp as a project, the findings suggest a need to focus on ways of enhancing the distribution, provision, usability and impact of its resources in view of the complexity and diversity of different carer circumstances. The findings also suggest a need to reconceptualise the kit not as a single, static product, but as a set of modular resources that can be flexibly deployed at different stages of the caring journey.

Such an approach would support more effective and targeted information provision at, for example, point of diagnosis, during periods of increasing care intensity, or end-of-life care, while reducing the risk of overwhelm. It would also enable clearer guidance for key connector points, including specialist services, councils, and community organisations, on when and how to introduce components of the kit.

Noteworthy also is that while the findings highlight challenges to achieving consistent and timely kit distribution, they also point to a clear opportunity for CarerHelp to more deliberately map and leverage key points of intersection along the caring journey (e.g. health services, councils, libraries, community events), where carers are most likely to come into contact with supportive organisations and be receptive to key information.

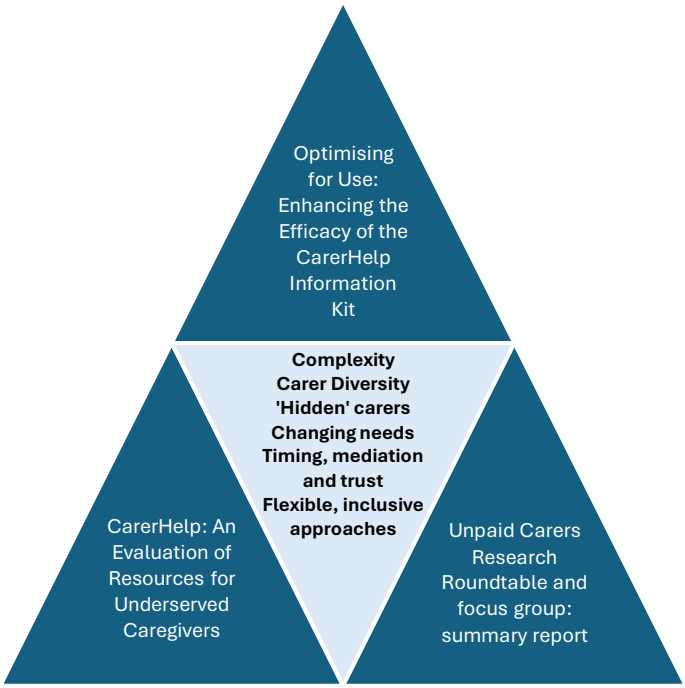
The seemingly contradictory view expressed by one of the carers regarding whether information should be provided early or introduced in a staged, modular way may also point to the value of more effective signposting such as a clear front-of-kit map or FAQ-style guide that helps carers quickly orient themselves to, and selectively access, the information most relevant to their immediate concerns.

Finally, the findings raise questions about how CarerHelp connects with related projects and initiatives within the broader carer support landscape. Strengthening alignment and coherence across programs may enhance visibility, reinforce messaging, and maximise impact, particularly for carers who are not engaged with formal care pathways.

Triangulation of findings

While the findings contained in this report yield important and valuable insights, triangulation with two other key RePaDD reports on carers' experiences – *CarerHelp: An evaluation of resources for underserved caregivers* [12] and findings from the *Unpaid Carers Research Roundtable and focus group* [13] – reinforce and strengthen several of the current study's key observations.

Across all three sources, there is a consistent finding that carers' needs are contextual, evolving, and often insufficiently recognised, which directly affects access to appropriate support. For example, *CarerHelp: An evaluation of resources for underserved caregivers* highlights the aim of improving access to relevant end-of-life information and strengthening carer wellbeing, particularly for underserved populations, through more effective targeting and better linkages to resources. This aligns with the *Carer Roundtable's* findings that many carers – such as those from non-English-speaking backgrounds and those in rural and remote areas are effectively 'hidden' in much the same way as those who do not self-identify as 'carers' (discussed in the current study).



The three sources also converge on the importance of timing, mediation, and relational trust in making information provision and research engagement effective. The current report demonstrates that even high-quality resources such as the CarerHelp Information Kit can be overwhelming or underutilised if introduced too early, too late, or without appropriate context,

and that selective, staged provision is more effective. Similarly, findings from the *Carer Roundtable* emphasise that carers are survey-fatigued and that meaningful involvement in research requires early engagement, clear explanations of research processes, and ongoing support, including wellbeing check-ins and debriefings. Together, these findings highlight that both information delivery and research participation depend heavily on trusted intermediaries – such as health professionals, service staff, and researchers – who can judge relevance, prioritise content, and support carers emotionally and practically. All three sources also point to the need for flexible, inclusive approaches that recognise carer diversity and the emotional impact of caring.

Limitations

This study has several limitations that should be considered when interpreting the findings. Most notably, the number of participants interviewed was comparatively small. While the number of people interviewed was sufficient generate rich, useable insights into how the CarerHelp Information Kit is used in practice, it limits the extent to which findings can be generalised across all service settings, geographic contexts, or carer populations. As with qualitative research more broadly, the emphasis of this study was on depth of understanding (rather than representativeness). The findings therefore reflect the perspectives and experiences of those who participated and should be viewed as indicative.

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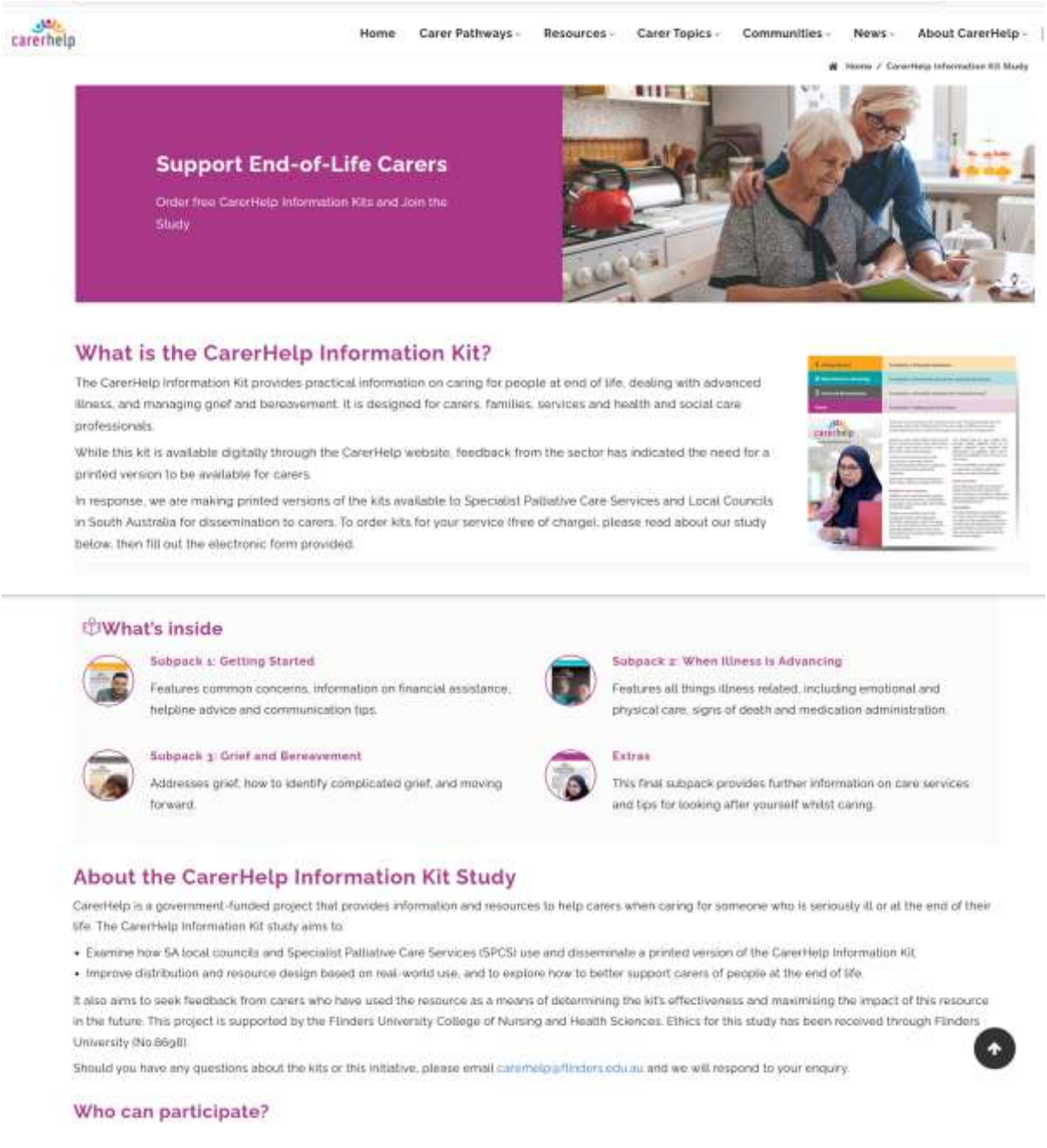
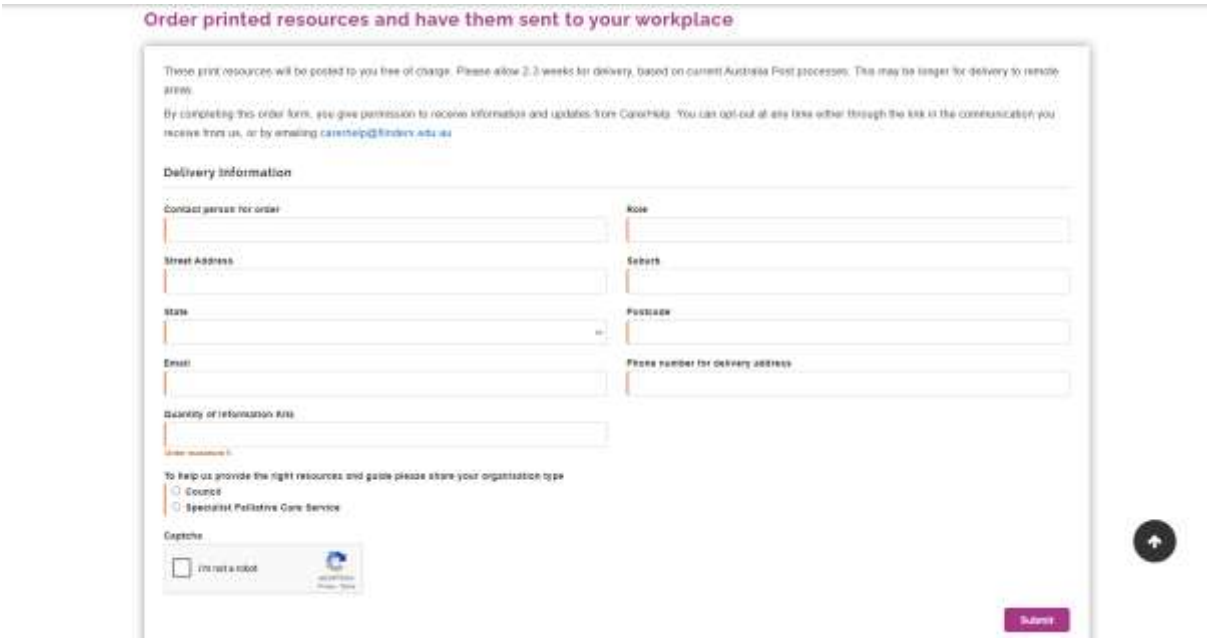
Appendices

Appendix 1: Landing Page (SPCS and SA Local Councils)





Appendix 2: Telephone Follow-Up Questions

- Can you please confirm that the CarerHelp Information Kit(s) we sent to you have arrived?
- If the Kit(s) has/have arrived, can you please tell us if they have been used or distributed in your organisation?
- Can you provide us with some feedback on your initial thoughts about the kits? Do you think that they might be useful for carers, SPCS or others?
- If they have been used or distributed, can you please tell us about how your organisation has used and/or distributed them?
- As explained in our email dated 24/07/2025, we are conducting a study investigating how SPCS use and disseminate a printed version of the CarerHelp Information Kit. We are also seeking feedback from carers who have used the resource.

- Would you, or someone in your organisation who could help us to learn more about how the kits have been used, be prepared to participate in a 30–45-minute interview?
- Have you been able to discuss the study with carers who may consider participating in an interview? We would welcome the opportunity to discuss the study with them.

Appendix 3: Study Information Sheet for Carers

carerhelp

Tell us if it helped

The CarerHelp Information Kit provides practical information on caring for people at end of life, dealing with advanced illness, and managing grief and bereavement.

The CarerHelp project which has developed the kit is funded by the Australian Government Department of Health, Disability and Ageing.

Why we're reaching out

We are sharing the CarerHelp Information Kit with palliative care services and local councils to help carers more easily access the Kit.

If you are a carer

As a carer, we are seeking your feedback on the Kit and whether it was useful to you. All carers taking part in an interview will be provided with a $50 gift card for their time and support.

How to take part

You can find out more about the study and make a time for an interview about the Kit by emailing CarerHelp@flinders.edu.au

You can also learn more about the study and read the Participant Information and Consent Form by visiting carerhelp.com.au/News

This project has been approved by Flinders University's Higher Research Ethics Committee (Project ID 8698)

ST VINCENT'S HOSPITAL MELBOURNE Flinders University Carers Australia

carerhelp.com.au CarerHelp is funded by the Australian Government Department of Health, Disability and Ageing.

Appendix 4: PICF (SPCS and SA Local Councils)

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Title:
CarerHelp Information Kit Study

Chief Investigator:
Professor Jennifer Tieman
CarerHelp Investigator
College of Nursing and Health Sciences (CNHS)
Flinders University
Tel: 08 7221 8237

Co-Investigators:
Dr Seth Nicholls
Research Fellow
CareSearch, CNHS
Flinders University
Tel: 08 8201 5869

Ms Ivy Guo
Marketing Officer
CarerHelp
Flinders University
Tel: 08 8432 4254

Description of the study
Caring for someone at the end of their life is an important role, helping not only the person cared for but that person's family, friends, and the community by reducing the pressure on our health care system. CarerHelp is a government-funded project that provides information and resources to help carers when caring for someone who is seriously ill or at the end of their life.

This study aims to examine how SA local councils and Specialist Palliative Care Services (SPCS) use and disseminate a printed version of the CarerHelp Information Kit. It also aims to seek feedback from carers who have used the resource as a means of determining the Kit's effectiveness and maximising the impact of this resource in the future.

This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study
The aim of this research is to understand how local councils and Specialist Palliative Care Services (SPCS) use and disseminate a printed version of the CarerHelp Information Kit, and seek feedback from carers who have used the resource.

The specific objectives are:

1. To track usage patterns of the CarerHelp Information Kit for two targeted groups: Special Palliative Care Services (SPCS) and South Australian Local Councils
2. To investigate how SPCS incorporate this palliative care resource for carers into their service work processes
3. To document how local councils identify those with carer responsibilities and make the resources available within their communities
4. To explore the value of print resources
5. To seek carer feedback on the resources through SPCS and local councils

Benefits of the study
It is anticipated that the data collected during this study will help CarerHelp maximise the impact of the CarerHelp Information Kit.

Participant involvement and potential risks
If you agree to participate in this research study, you will be asked to:

- Attend one online interview (via telephone, Zoom, or MS Teams).

The interview will last for around 45-60 minutes. Participation is entirely voluntary.

The researchers do not expect the questions to cause any harm or discomfort to you.

Withdrawal Rights
You may decline to take part in this research study. If you decide to take part and later change your mind, you may withdraw at any time without providing an explanation. To withdraw, you may contact the Chief Investigator, or you may simply leave the interview.

Please note that once any information provided by you during your interview has been analysed, promoted and published (including any illustrative or thematic comments), this data may not be able to be withdrawn. You do, however, have the right to withdraw from the study and have your interview data removed prior to this.

Confidentiality and Privacy
The research outcomes may be presented at conferences, written up for publication, or used for other research purposes as described in this information form. No identifying information will be included in these research outcomes.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent. You will be able to view the transcript of the interview.

Data Storage
All Information collected (including any personal information) will be stored securely on a password protected computer and/or Flinders University server throughout the study and for a period of five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?
Findings from the study will be shared on the CarerHelp website and through project newsletters and various other media when completed. On project completion, a short summary of the outcomes will also

be provided to participants via email.

Conflict of Interest
Because the Chief Investigator is affiliated with the CarerHelp, CareSearch and End of Life Directions for Aged Care (ELDAC) projects, a potential conflict of interest is unavoidable as the projects and the investigator are known to many health professionals in the sector. To reduce the impact of this, interviews will be conducted by a third party (Dr. Seth Nicholls, CareSearch Research Fellow) and participants will be informed of the nature of the research project and encouraged to give open and honest responses.

Ethics Committee Approval
The project has been approved by Flinders University's Human Research Ethics Committee (Project No. 8698).

Queries and Concerns
Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 2543 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet which is yours to keep. If you accept our invitation to be involved, please sign the enclosed Consent Form and email it to seth.nicholls@flinders.edu.au

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that I will be unable to withdraw my data and information from this project once any information I have provided has been analysed, promoted and published. I also understand that this data **will be used** for this research study.

I further consent to:

☐ Participating in an interview
☐ Having my information audio and/or video recorded
☐ My data and information being used in this project

Signed:

Name:

Date:

Appendix 5: PICF (Carers)

Flinders University

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Title:
CarerHelp Information Kit Study

Chief Investigator:
Professor Jennifer Tieman
CarerHelp Investigator
College of Nursing and Health Sciences (CNHS)
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Research Fellow
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Flinders University
Tel: 08 8201 5869

Ms Ivy Guo
Marketing Officer
CarerHelp
Flinders University
Tel: 08 8432 4254

Description of the study
Caring for someone at the end of their life is an important role. CarerHelp is a government-funded project that provides information and resources to help carers when caring for someone who is seriously ill or at the end of their life. This study wants to understand how carers use a printed information kit provided through local councils and Specialist Palliative Care Services (SPCS). Your views and feedback will help improve the information kit.

This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study
The overall aim of this research is to understand how local councils and Specialist Palliative Care Services (SPCS) use and disseminate a printed version of the CarerHelp Information Kit. The aim of this part of the research is to seek feedback from carers who have used the resource.

The specific objectives are:

1. To track usage patterns of the CarerHelp Information Kit for two targeted groups: Special Palliative Care Services (SPCS) and South Australian Local Councils

inspiring achievement

2. To investigate how SPCS incorporate this palliative care resource for carers into their service work processes
3. To document how local councils identify those with carer responsibilities and make the resources available within their communities
4. To explore the value of print resources
5. To seek carer feedback on the resources through SPCS and local councils

Benefits of the study
It is anticipated that the data collected during this study will help CarerHelp maximise the impact of the CarerHelp Information Kit.

Participant involvement and potential risks
If you agree to participate in this research study, you will be asked to:

- Attend one online interview (via telephone, Zoom, or MS Teams).

The interview will last for around 45-60 minutes. Participation is entirely voluntary.

Discussing caring, serious illness and end of life can be difficult. We will provide you with contact information for counselling if the interview raises concerns for you.

Remuneration
Carers who participate in an interview will be provided with a $50 gift card. This card will be sent to the participant's nominated address.

Withdrawal Rights
You may decline to take part in this research study. If you decide to take part and later change your mind, you may withdraw at any time without providing an explanation. To withdraw, you may contact the Chief Investigator, or you may simply leave the interview.

Please note that once any information provided by you during your interview has been analysed, promoted and published (including any illustrative or thematic comments), this data may not be able to be withdrawn. You do, however, have the right to withdraw from the study and have your interview data removed prior to this.

Confidentiality and Privacy
The research outcomes may be presented at conferences, written up for publication, or used for other research purposes as described in this information form. No identifying information will be included in these research outcomes.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent. You will be able to view the transcript of the interview.

Data Storage
All Information collected (including any personal information) will be stored securely on a password protected computer and/or Flinders University server throughout the study and for a period of five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

Findings from the study will be shared on the CarerHelp website and through project newsletters and various other media when completed. On project completion, a short summary of the outcomes will also be provided to participants via email.

Ethics Committee Approval
The project has been approved by Flinders University's Human Research Ethics Committee (Project No. 8698).

Queries and Concerns
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Thank you for taking the time to read this information sheet which is yours to keep. If you accept our invitation to be involved, please sign the enclosed Consent Form and email it to seth.nicholls@flinders.edu.au

CONSENT FORM

Consent Statement

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☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that I will be unable to withdraw my data and information from this project once any information I have provided has been analysed, promoted and published. I also understand that this data **will be used** for this research study.

I further consent to:

☐ Participating in an interview
☐ Having my information audio and/or video recorded
☐ My data and information being used in this project

Signed:

Name:

Date:

Appendix 6: Interview Guide (SPCS)

- Can you tell me a little bit about your service? (Size, location, number of patients etc)
- What would be the usual way that patients come to your service? (referral, stage etc)
- How and when do you identify the carer? Do you meet separately with them?
- What information needs do your carers have and how do you support them?
- Have you had a chance to include the CarerHelp Information Kit in your practice?
- [If so] How do you use it? When do you provide it? Do you remind carers of it or highlight different sections at different times?
- What things do you think work well about the Kit? What could be improved?
- Do you think there is a benefit in having printed resources that can be handed to a carer? What are they?
- What else could we (CarerHelp) do to support the information needs of carers?

Appendix 7: Interview Guide (SA Local Councils)

- What services does your council provide for carers, particularly older people and people who are seriously ill?
- How do you identify carers and/or connect with carers in your community?
- How would you share the CarerHelp Information Kit with a carer or family member?
- Do you make the Kits openly available or is it generally in the context of a discussion or an event?
- What other resources do you think could be helpful for councils given an ageing population and the care needs of seriously ill people?

Appendix 8: Interview Guide (Carers)

- Can you tell me a little bit about your caring role?
- How do you feel about using a term like “carer”? Do you think it helps services and organisations understand your role and relationship with the person you are caring for?
- We have learned that carers have many different needs. How important is having access to information to you?
- What have you found to be the most useful information that has helped you as a carer?
- People find and use information in different ways. What would be the best way to help carers have information they need when it is needed?
- Is it helpful when information is provided by one of the health care team?
- Do you think having the healthcare team provide information is a good way to help carers get information?
- Where would you have time to have seen or found information about caring and/or palliative care?
- What else can we do to support carers looking after someone who is seriously ill?