

Improving Carers' Quality of Life

A resource for health professionals working in palliative care to

- understand the full impact of the caring role
- develop prevention strategies

This resource would not have been possible without the insights and knowledge of Jan Campbell, former welfare worker at South East Palliative Care. Thank You also to the team at the Southern Metropolitan Region Palliative Care Consortium for their assistance with editing and layout.

Robyn Reid
Motor Neurone Disease Project Worker
Southern Metropolitan Region Palliative Care Consortium (SMRPCC)
April 2016
Website: www.smrpalliativecare-consortium.org.au



DISCLAIMER

The information contained therein may be subject to change and those affected should always seek advice from the appropriately qualified professional or agency. Consult with solicitors or allied health workers or the agency that is relevant to the information required.

Contents

| | |
|--|----|
| 1. Introduction | 1 |
| 2. On becoming a carer | 2 |
| 3. The impact on practical aspects of life | 3 |
| 3.1 Financial | 3 |
| 3.2 Legal | 6 |
| 3.3 Immigration and visas and the impact on carers..... | 7 |
| 3.4 Children of carers and children as carers..... | 8 |
| 4. The impact on health | 10 |
| 4.1 Well-being | 10 |
| 4.2 Fatigue..... | 10 |
| 5. Reducing the impact | 12 |
| 5.1 Carer education..... | 12 |
| 5.2 Respite | 13 |
| 5.3 Caring after hours | 13 |
| 5.4 Preparing for the death..... | 14 |
| 5.5 Bereavement..... | 14 |
| 6. Carer assessment | 16 |
| 6.1 Carer assessment tool..... | 16 |
| 6.2 Referral..... | 17 |
| 7. Resources | 19 |
| 8. Bibliography | 22 |
| 9. APPENDIX 1 – Commencing Caring Conversation Checklist | 23 |

1. Introduction

Carers contribute over \$20 billion a year to the Australian economy. In Australia, nearly 2.7 million people (12%) aged 15 years and over are involved in informal care of children, adults and older persons with chronic and terminal conditions (ABS,2012). Carers' contributions have been acknowledged in the development of the Victorian Charter, Supporting People in Care Relationships 1(2012). For specialist community palliative care agencies, carers are essential to achieving the client's goal of 'place of care' - especially if they wish to remain at home.

Caring for a loved one can be meaningful and rewarding, but research indicates that the burden of caring can be costly for well-being and health. Carers are at risk of physical injury, anxiety and depression and a reduction in social connectedness. Caring for someone with a life-limiting illness can jeopardise financial security and emotional, mental and physical well-being. The decision to care for someone, made in the early stages of the disease may have unforeseen consequences that are far-reaching.

Traditionally palliative care clients were those with mainly malignant diseases. Currently, services increasingly admit people with chronic diseases. Their carers may be in the role for much longer.

Palliative care staff must be aware of the needs of carers, and service models need to include carer assessment and referral throughout the journey of care, including post bereavement.

This resource has been developed to support palliative care specialists to understand the issues of carers. It outlines various arenas of decision-making and discussion that may be relevant to carers and their loved ones, as they negotiate the impact of a life threatening disease.

Please note: this resource is not meant for carers. The Centre for Palliative Care has produced a resource for this purpose: *Supporting a person who needs palliative care: A guide for family and friends.*

It is important to improve awareness of carer needs and issues so that appropriate assessment, adequate monitoring and referrals when relevant are undertaken to prevent carer burnout and poor carer health outcomes. The quality of life of the person in palliative care is dependent on the well-being and capacity of their carers.

¹ http://www.dhs.vic.gov.au/__data/assets/pdf_file/0010/738667/91-The-Victorian-charter-supporting-people-in-care-relationships.pdf

2. On becoming a carer

Many people willingly take on the role of carer and find the experience of caring rewarding and deeply meaningful. However, at times, carers consent to providing care at home without having considered what caring for a loved one can mean for their life and if there are alternative options. In order to provide carers with a real choice it is necessary to ensure they understand the situation they are in and what is demanded of them and potential consequences.

It is also possible that the needs and expectations of the client and their carer differ and this may never be openly discussed. The dynamics of the relationship and the congruence or otherwise of those needs can greatly influence bereavement and carer outcomes. It is important that there is an adequate assessment of both the carer and cared for in order to pre-empt any crises or disruption to care. This requires an advanced level of communication skills and appropriate allocation of time and resources.

Carers are under considerable strain at times. The opportunity to talk to a health professional about what is happening and in particular to anticipate what may happen with respect to the management of the illness and the dying process is very important. This discussion is difficult while in the presence of the person cared for, especially if there is conflict or differences in understanding the trajectory of the illness. It may be beneficial for carers to have their own counselling support independently of those involved with the person receiving palliative care.

It may be helpful to outline alternative caring possibilities at the outset of the caring role. These include:

- respite options
- inpatient palliative care service
- residential aged care *etc*

This can introduce the idea that changes can occur to care arrangements and that options are available.

3. The impact on practical aspects of life

3.1 Financial

Carers may need to reduce or give up employment in order to attend to the demands of caring. This may adversely affect their financial capacity in both the short term and long term. There are also added pressures of medical, equipment, transport and medication costs. Carers may have differing levels of financial literacy and may need extra assistance to understand the importance of being proactive to organise their finances. There is often also a need for advocacy with government departments because a lack of assertiveness or knowledge can lead to disadvantage.

If carers fail to consider financial matters this can have serious consequences for the financial viability of the family. Should the person they are caring for become unable to communicate or incompetent, vital information may not be available or there may be a stressful and lengthy process to obtain the legal right to administer their affairs and there may be financial disadvantage incurred as a result.

Financial counselling at no charge or low cost is offered by some community agencies, community legal services and government agencies.

Ambulance cover

It is essential that palliative care clients have *ambulance cover*. Some clients, especially migrants and refugees, might not be aware that calling the ambulance without cover will incur costs. Even for health care card holders it is advisable to have ambulance cover, because certain services may not be covered.

Changes to income

If it is necessary to stop work then income will need to be examined to determine how to meet costs. There are two types of payments that carers may be able to access – Carer Payment and Carer Allowance.

The Carer Payment provides an income support payment (similar to a pension) for people who are unable to participate in the paid workforce because they're caring for someone. It is permissible to work for up to 25 hours including travel time while receiving these benefits. For more information please follow this link. *Carer Payment*.

The *Carer Allowance* provides an income supplement payment for people who provide daily care. It can be paid even if working and on top of pensions. It is not means tested.

The Department of Human Services can also give information including, but not limited to:

- *rent assistance*
- *the Age Pension*
- *concession cards*

They also provide a free independent *financial information service* which you can access, even if you're not receiving a pension or benefit.

Mortgage

If there is a mortgage and income is reduced then the following may be considered:

- accessing the total Permanent Disability insurance on a Superannuation policy
- accessing income protection if available
- discussing the situation with the bank to organise an interest only loan for a period of time
- if renting, the family may be eligible for rent assistance
- using the equity in a home for short term measures (increase the mortgage)
- accessing mortgage insurance/income protection insurance

Bills

For people who receive Centrelink payments, it is possible to get bills deducted from income on a fortnightly basis which reduces the stress of large bills. Centrelink will do this via their scheme called *Centrepay*.

If appropriate, change the bills into carer's name so they can administer accounts. Note: Due to privacy procedures an account will only be discussed with the person who has initiated the service. If this is the palliative care client, both the carer and client will need to take part in discussions with the provider.

Community Information Centres provide vouchers for food and telephone calls in times of financial hardship.

The **Utility Relief Scheme** run by the Department of Human Services provides for assistance with utility bills for people who receive Centrelink payments.

UTILITY RELIEF SCHEME

If utility bills are over a \$100 and NOT paid by regular instalments e.g., by Centre pay (fortnightly instalments taken from a Centrelink pension), a regular fortnightly direct debit or payment at the post office, people are eligible for this scheme and the whole amount of each of the gas electricity and water will be paid in full up to \$500.00 each bill.

People accessing the scheme must hold a pensioner health care card but those on low incomes or with financial hardship will also be considered. There are three categories:

1. recent decrease in income
2. a significant increase in consumption e.g., extra electricity use due to the need for extra heating
3. high unexpected expenses for essential items such as medication or equipment

Once this scheme is used it can only be accessed every two years and the utility company prefers that arrangements for regular fortnightly instalments are made thereafter.

A Utility Relief Form may be obtained from their website (see above).

If there are many and difficult issues with respect to finances seek out financial counselling.

Banking

The following issues are essential to organise:

- the house title must be in joint names and not Tenants in Common as this impacts on the house being left to the surviving partner
- any bank accounts must be able to be accessed with a signature by either person so that two signatures are not required to access funds
- there needs to be an Enduring Financial Power of Attorney so that finances can be attended to on behalf of the person who is sick if they are unable to do so
- a will is very important. If a person dies without a legal will, they are deemed to have died **intestate**. This means that a surviving partner will not automatically inherit the estate. This could seriously jeopardise the family's security

Superannuation

Be sure that there is a current **binding nomination** with the Superannuation Company stating the division of the benefits. Superannuation is not administered according to a will and others may make a claim if they have had a co-dependent relationship with the deceased. Children of a prior marriage may also have a claim if they have been supported by the deceased.

Financial issues after death

This is a very difficult personal time, made more challenging by the fact that changes in finances occur rapidly after death. Ideally, the financial circumstances of the family have been adequately assessed prior to this time. It is critical that carers, if necessary, have access to allied health professionals who can take the time to advocate on the carers behalf. Social workers or welfare workers or even trained volunteers can assist by writing letters to creditors, fee paying schools, etc.

If finances are a problem, the carer may be eligible for funeral company *bereavement assist* through Centrelink for some funeral expenses. It is important to check the conditions carefully

There is no longer a widow's pension for people born after 1955. This means that following 12 weeks of bereavement if the person does not have a source of income and needs to go onto a benefit they will commence on the *Newstart Allowance* from Centrelink and must look for work. This can be difficult if the carer has not been in the workforce or lacks skills but also because they may have difficulty looking for employment while managing their grief.

Carers who are employed may need to consider taking leave from work rather than resigning so that they may resume work either returning to their prior duties, or working part-time post bereavement.

3.2 Legal

The following legal documents are important to consider, depending on the circumstances of the family. These documents can be prepared without assistance, but some people may benefit from consulting the following:

General Practitioner

- **Advance Care Plan**- capturing values and wishes regarding treatment decisions and outcomes as the illness progresses.
- **Refusal of Medical Treatment** document signed by the treating doctor to limit life-preserving measures, medical treatment generally or to refuse a specific kind of medical treatment

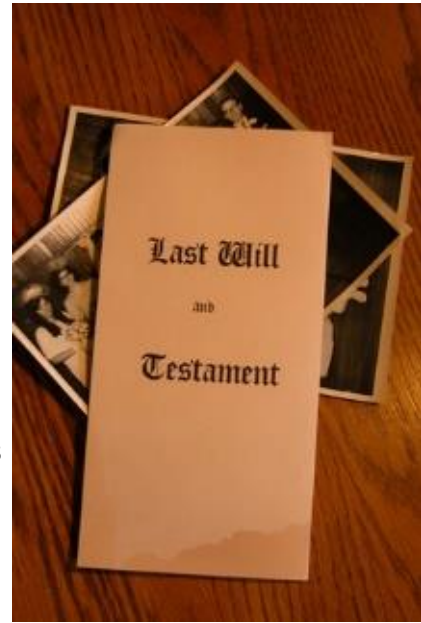
Solicitor (or community legal centre if appropriate)

- making a **Will**
- **Enduring Power of Attorney** for capacity to manage financial affairs on behalf of their loved one should they no longer be able to do so themselves. This ceases after death and the executor will take over.
- **Enduring Medical Power of Attorney** to make decisions about treatment if their loved one is no longer able to.
- **Guardianship** arrangements for children who may be left without a parent or relative to care for them or to take over a person's affairs in the absence of legal instructions when they cannot manage their affairs competently. *State Trustees* can be engaged to manage affairs if there is no-one to do it.

Legal issues after death

Probate – Probate is a document issued by the court, if the estate is over a certain amount, certifying the Will's validity and confirming the appointment of an Executor to administer the deceased estate. The court requires proof that the Executor appointed in the Will is alive, willing and competent to undertake the tasks involved. Also, it is important to verify that the document is the *last* Will made by the deceased and that there are no objections to that Will. Without probate assets can't be distributed.

If the **Will is invalid** then they will need to apply for Letters of Administration and advertise in the paper for 6 weeks. Letters of Administration is the court's approval to administer the estate of a person who dies without a Will. In most instances Letters of Administration will be granted to the next of kin of the deceased e.g. a spouse, domestic partner or a child of the deceased.



3.3 Immigration and visas and the impact on carers

People who have arrived in Australia as immigrants or refugees have many issues relating to accessing and utilising the health system. Prior to arrival in Australia they may have experienced psychological and physical trauma, deprivation, unhealthy environmental conditions and disrupted access to health care which may reduce their ability to trust service providers and negotiate the health system. There may be language, cultural and financial barriers reducing their ability to receive effective health care.

People who do not have English as their first language may have poor health literacy and less ability to negotiate the health system. Adequate use of professional interpreters is necessary to ensure information is received and understood and allow people to communicate specific cultural needs.

People without permanent residency may become a health care user while not eligible for Medicare. They may be required to pay for all associated costs of medical treatment, however most public health services in Victoria will provide services without charge.

Some carers also may not be permanent residents. If there is a visa application in process it is important to seek advice about any status change of the application if the visa is linked to the person who is likely to die. The [Migrant Resource Centre](#) or an immigration agent may provide advice.

In the case of refugees and asylum seekers who have experienced trauma and torture, some clinical procedures may remind them of abuse/torture. Following the death of a spouse some carers may have to seek work which they may never have done before in Australia. They may lack language,

computer and work related skills and reduced social support. There are also restrictions on access to welfare payments for immigrants. (Finney *et al*)

Migrant Resource Centres offer intensive settlement services for refugees and migrants for the first five years after their arrival (see *Resources* for contact details). For health professionals assisting carers who are immigrants and refugees, their needs and issues are complex. Care must be taken to ensure cultural competency as well as understanding issues within communities when attempting to liaise with ethno-specific support services.

3.4 Children of carers and children as carers

Many carers are looking after children while dealing with a palliative care situation. Children's need for age appropriate information and support may be overlooked due to fatigue, exhaustion, lack of understanding or time. Parents may wait for children to raise issues unaware that children are often acutely aware of the burdens that parents are carrying and may not raise issues in order to be helpful or not make further demands. **The Cancer Council** has published a resource called: **Talking to Kids About Cancer** which is available on their website. It also contains helpful hints to be used with non-malignant terminal illnesses.

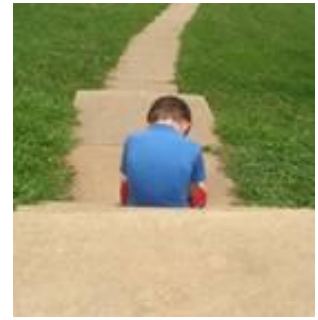
Parents and grandparents may require assistance with talking about the person's illness, death and dying. Practical support for parenting can come from family and friends and from the community. Schools have access to their own social workers and psychologists. It is important to inform welfare staff in the school about the home situation to ensure optimal support of the child. This support is offered in school hours which reduces the need to travel to yet more appointments. Liaison with welfare staff in schools can reduce the workload for welfare staff in palliative care agencies.

Teachers also need support to best assist the child both before and after bereavement. The impact of the child or young person's situation may lead to cognitive, emotional and behavioural challenges and it is very helpful for teachers to know what their students are experiencing.

They can alter expectations and work requirements and provide ongoing support. Post bereavement, classmates benefit from discussion about how best to support the child or young person. Normal routines can provide great benefit for children in difficult situations. **The Cancer Council** has developed a resource for school communities around supporting students.

Many children and young people are also carers, either by themselves or in conjunction with their family. These young carers may work physically at home doing housework, cleaning and cooking while attempting to complete schoolwork and leisure activities. They may become isolated and unable to participate in age appropriate activities either due to the demands of their caring role or because of transport or financial constraints.

They may be required to stay at home missing school which may, over time, significantly reduce their educational outcomes. There may be pressure from family or cultural expectations that mean the young carer may leave school early and not complete education. It is critical that young carers are identified and that they have access to extra resources and support.



Canteen is a charity that provides resources and support for young people between 12-24 who have been effected by cancer, including young carers..

4. The impact on health

4.1 Well-being

Given the lengthy and difficult nature of caring it is beneficial to provide appropriate carer support. Much of the practical support can be provided by friends and family though the carer may be reluctant to take up offers of help. Other community connections such as religious groups, clubs, schools and networks may be able to offer assistance with various needs. This website is an example of how help can be organised: [*Lotsa Helping Hands*](#)

Social media and email can provide information for and connection to friends and family, minimizing intrusion through constant requests for updates. The carer may tell a small group of people about the daily status of the person who is ill and then those people can circulate the information ensuring it is accurate and up to date.

Physical activity is important to maintain well-being. This may include a social game of sport, time at the gym or a walk around the neighbourhood. Physical activity can assist with the processing of emotions and provide a healthy outlet for frustration and sadness. Participating in hobbies and pastimes can be vital. Maintaining social connections is also an important protective factor for grief post-bereavement. Participating in specific interests reinforces the sense of self and separateness that increases the capacity to cope with the demands of caring. Many carers are reluctant to do something for themselves, however it is very important that the carer takes a break from caring and maintains social connectedness. It is important that they understand that accepting some form of respite can help them maintain their ability to care.

4.2 Fatigue

Sleep deprivation and interrupted sleep may cause health issues in the carer. She/he may also become fatigued and irritable which will impact on capacity to care. The carer may also feel guilty for being less able to tolerate the caring role. All of this impacts on the one being cared for and the extended family members. Fatigue increases the risk of accident and injury as well as comprehension of instructions and the ability to carry out tasks (driving, handling medications, etc).

It is difficult for carers to discuss their situation and feelings while in the presence of the person they are caring for as they may feel disloyal or guilty. Time away from the role of caring rejuvenates the carer and provides a rest from the demands of being on call. Time out enables the person to share their issues with trusted friends and loved ones and gain support.

Volunteers in palliative care agencies can be an invaluable source of support to enable carers to have a break or continue their desired activities. Respite provides a break from caring and is an important factor in making sure the carer role has some longevity.

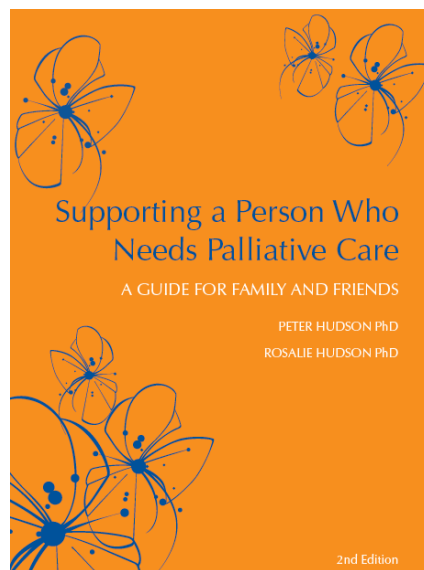


5. Reducing the impact

5.1 Carer education

Carers may have limited medical and nursing knowledge therefore it is important to discuss the tasks and issues of providing palliative care in the home. This is best discussed at the time of the referral.

Carers may need education about nursing tasks, equipment, disease progression, medications, after hours care, the process of dying, emotional and psychological impacts on them and their loved ones, resources and services, financial and legal issues as well as funerals and care of the deceased. There a number of resources available (*such as the Loddon Mallee Carers Kit*) that can help re-inforce carer education and some palliative care agencies chose to run *carer education groups*. It is important to carry out an assessment of carer capacity to ensure their safety and that of their loved ones. Consider the context of the burden of caring, when the carer is least able to manage their changing situation amidst multiple losses and demands.



5.2 Respite

Respite can be targeted to the needs of an individual and reach from a few hours to days or weeks. It can provide relief for both the carer and the person being cared for. The person being cared for may take comfort in being able to 'help' the carer and may welcome interaction with new people.

- Palliative care may offer respite via volunteers. Volunteers can allow carers to shop, participate in social activities, attend medical appointments or just have some time alone.
- Palliative care services may also arrange for overnight or day respite with a nurse so that the carer can take a break from caring.
- Local Governments can offer respite services, transport and home help and other sources of support. Some of these are means tested and/or need referral from a GP.
- Private agencies may offer respite on an ongoing basis according to income and needs.
- The Commonwealth funds services on a regional basis to provide support including respite for carers. The Southern Metropolitan service is called '*Alfred Health Carer Services*'
- Family and friends can be a great source of help with meals, comfort and assistance. This presupposes that carers feel able to ask for help.
- People over 65 may be eligible for a home care package. Contact the *local ACAT*

Carers should be assessed for support systems and encouraged to obtain help from others so that they can continue to care for their loved one at home. Family and friends often feel helpless in the face of a life threatening illness and allowing them to help can alleviate that feeling. It also ensures that carers and loved ones remain engaged and do not become isolated due to others discomfort with their situation.

5.3 Caring after hours

After hours, especially at night, caring at home can be more difficult especially when the carer is not well prepared. Adequate care planning prior to any after-hours emergency is essential to minimise trauma or unnecessary admission to hospital emergency. This includes

- the assessment of the carers skill
- the ability to management symptoms
- information about who to call (consider interpreting services)
- the availability and knowledge of administering emergency medications and
- the availability of any relevant documentation, such as Advance care plans and Refusal of Medical Treatment documents

It could also be beneficial to consider if there is someone (a neighbour or friend) who could assist the carer in an unplanned event after hours.

5.4 Preparing for the death

It is important to prepare the family for what happens during and after the dying process. Hopefully this can be a gentle and extended process within the context of a respectful relationship between client, carer and palliative care staff. The degree of information and education will depend on the carers and clients willingness to be open about their prognosis. Where the issue of death and dying cannot be broached, care and discretion are required to meet the carer and client's needs tactfully, while continuing to provide support.

Carers need to be aware of their options around care in case they are unable to continue caring at this time or in the case of symptoms which are unable to be managed at home. This may require continual contact and reassessment and more intensive levels of support by palliative care staff.

Information about the stages of dying and the likely cause of the death should be discussed along with how to manage the point of death and the supports available at the time. Carers should have information about care of the body and permission to attend to their personal emotional, psychological, spiritual and cultural needs. They should know what happens after death, i.e. who to call, how to obtain the death certificate if appropriate and the process for commencing funeral proceedings.

5.5 Bereavement

Best practice for caring for carers in palliative care currently includes a bereavement risk assessment². It is usually carried out and monitored by the palliative care team to ensure that the carer is provided with appropriate post-bereavement support.

The carer may also be of poor health, exhausted and overrun by the many demands before the bereavement occurs, adding to the burden of grief. The financial state of the carer may dictate a radical change in lifestyle and the possibility of the need to acquire new skills and carry out tasks which they may never have attempted before. They may experience changes, not only about their outer world but their inner one as they adjust to life without their loved one.

All of this takes place at a time of least clarity and confidence as well as ongoing problems with concentration, sleep, social and family concerns. The period post-bereavement may find the carer at a loss as they relinquish their caring role and readjust to once again having time on their hands. They may have become disconnected from their social groups or be radically altered in terms of their lifestyle and needs.

Carers may feel guilty about how they carried out their role or about possible feelings of relief on the death of the loved one. They may be at a loss as to how to navigate as a single person after many

² Hall C, Hudson P, Boughey A2012, *Bereavement support standards for specialist palliative care services*, Department of Health, State Government of Victoria, Melbourne.

years as a spouse or partner. They may find the needs of their children hard to meet in the wake of the impact of their own grief and may need extra assistance with information and education around how to relate to and support themselves and grieving family members.

They may need to take on roles and skills they have never had to do before at a time when grief affects their ability to cope and to learn new things.

Caring for the carers is a vital part of quality care and ensures that at the end of the caring role the impact of the tasks of caring has been mitigated as much as possible. It is necessary for post bereavement carer circumstances to be taken into account in order to cater for lifestyle changes after the death of the loved one. Early carer assessment with adequate time and allocation of resources is required to ensure that the outcomes for carers, particularly around poor mental and physical health, are improved wherever possible.

Palliative care staff who may have been part of the care team may also need to consider the impact of the death of the client and their relationships with their carers post-bereavement. They may need to take time to reflect or ritualise the end of these relationships in a way that optimises their well-being and reduces burn out.

The [Australian Centre for Grief and Bereavement](#) can provide more information and training.



6. Carer assessment

Health professionals may not be fully aware of carer's issues as they may make assumptions about the carer's knowledge and skill based on the fact that the carer has been a consumer of the health system for some time. Often the client and the carer are viewed as one unit. Without formal assessment tools, there is the possibility that the Health practitioner leads the conversation about when and which areas to discuss.

It is important to note that assessment is not a one-off event but an ongoing process of monitoring that encourages carers to identify and communicate their needs.

If needs have been identified that cannot be met by the palliative care agency, community resources and interagency collaboration should take place.

6.1 Carer assessment tool

In 2012, the Department of Health commissioned a report to assess clinical tools and endorsed the '*Carer Support Needs Assessment Tool*' (CSNAT). It is an evidence-based tool, designed for carers supporting someone at home towards the end of life. It was developed by Dr Gail Ewing, senior researcher at the Centre for Family Research, University of Cambridge, and Professor Gunn Grande, University of Manchester. Both have long experience of palliative and end of life care research, particularly with carers.

The tool has been designed to be short and simple to use for both carers and practitioners and comprises 14 broad support domains in which carers commonly say they require support.

The CSNAT differs from other carer assessment tools in that the process is facilitated by the practitioner, but led by the carer. This ensures that the response to the support needs identified by the carer is tailored to their individual needs. It uses a simple question and answer format to ask carers which areas they need more support with. The 'visibility' of common areas of support provided by the tool has been found to be helpful for carers. Then they can indicate whether or not they need more support in relation to each domain.

The CSNAT is copyright but available free of charge for use by practitioners supporting carers. The team behind its development also provide training and support for services wishing to implement the CSNAT. For further information visit the website: [Carer Support Needs Assessment Tool](#)

Positive impact of the clinical assessment tools

- the tool can open up conversations that otherwise would not have happened
- it can be useful where a carer finds it difficult to talk about the impact of caring
- it makes the carer's needs transparent and more legitimate
- it can cover the range of carer's issues quickly and thoroughly
- it may flag issues that reduce the need for crisis calls to the agency and reduce contact time overall
- because of the format, different health professionals may help the carer to fill it out so that it can be done at any contact time and the information used to refer to the appropriate person or agency

Challenges/barriers

At times it can be difficult to introduce a new clinical tool into the palliative care service model. Here are a number of barriers that may impact on the successful implementation of a carer assessment tool:

- staff may feel that they already provide appropriate informal assessment
- anticipation of an increase in workload
- assessing carers may take up time from agency resources
- fear of not being able to address issues raised
- carers may be reluctant to receive their own assessment
- carers may not want to talk about certain areas of their lives

While most health professionals believe they cover the areas on the tool, a more formal assessment means all areas are covered at once and systematically. (G. Emery University of Cambridge). Some research suggests that carers may not be fully aware of the impact of caring themselves and a tool may raise new issues (some carers find this unhelpful, while others are very gratified to see their issues addressed).

6.2 Referral

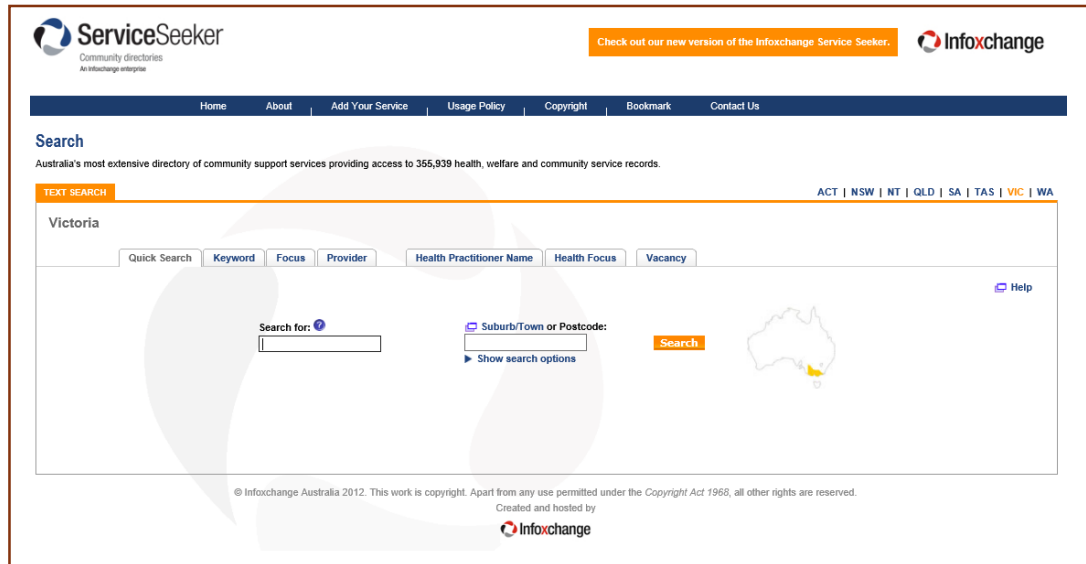
While there is plenty of research about the burden of caring, there is little evidence about interventions that may be beneficial. Nevertheless, it is critical that palliative care staff are familiar with the need to provide appropriate, proactive and informed responses to the needs of carers. This includes providing access to practical support across a range of areas, some of which may lay outside their area of expertise.

The website below is an initiative by the Victorian Government, which can assist staff to find the right type of assistance for the carer:

Service Seeker Community Directories

The website allows searches by topic area and location. It is important not to only provide the carer with contact details for the service, but to facilitate access if appropriate and to follow up if the intervention has led to anticipated results.

Service Seeker Community Directory



The screenshot displays the Service Seeker website's search interface. At the top left is the Service Seeker logo, and at the top right is the Infexchange logo with a banner that reads "Check out our new version of the Infexchange Service Seeker." Below the logos is a navigation menu with links for Home, About, Add Your Service, Usage Policy, Copyright, Bookmark, and Contact Us. The main heading is "Search", followed by the text "Australia's most extensive directory of community support services providing access to 355,939 health, welfare and community service records." A "TEXT SEARCH" tab is active, and there are links for ACT, NSW, NT, QLD, SA, TAS, VIC, and WA. The current location is set to "Victoria". Below this, there are search filters: Quick Search, Keyword, Focus, Provider, Health Practitioner Name, Health Focus, and Vacancy. A "Help" link is also present. The search area contains two input fields: "Search for:" and "Suburb/Town or Postcode:", both with "Search" buttons. A "Show search options" link is located below the second input field. To the right of the input fields is a map of Australia with a yellow dot indicating the current location in Victoria. At the bottom of the page, there is a copyright notice: "© Infexchange Australia 2012. This work is copyright. Apart from any use permitted under the Copyright Act 1968, all other rights are reserved. Created and hosted by Infexchange".

RESOURCES

GENERAL

| Hyperlink text | URL | Description |
|--|---|---|
| Ambulance Cover | www.ambulance.vic.gov.au/Membership.html | Ambulance Victoria membership - protects against the high cost of transport and treatment |
| Australian Centre for Grief and Bereavement | www.grief.org.au/ | Bereavement support, resources and information |
| Cancer Council – How We Can Help | www.cancervic.org.au/how-we-can-help/phone-support | Resources for Family Carer Support |
| Carer Support Needs Assessment Tool | http://csnat.org/ | For information regarding use of the CSNAT |
| Carers Victoria | www.carersvictoria.org.au/ | Multiple resources and support services for carers |
| Centre for Palliative Care | http://centreforpallcare.org/search/d503f4230ff90561b979a087181bbced/ | Resources for Family Carer Support |
| Evidence based strategies for family support - paper | http://centreforpallcare.org/assets/uploads/Evidence_based_strategies_and_resources_for_family_carer_support_2014.pdf | Available resources for evidence based strategies for family support. |
| Decision Assist | www.caresearch.com.au/caresearch/tabid/2583/Default.aspx | Telephone service to help with advanced care plans and palliative care (over 65 only). Operates 8am – 8pm seven days a week. |
| Lotsa Helping Hands | lotsahelpinghands.com/how-it-works/ | Information on community assistance for carer e.g. meals for the family, rides to medical appointments, or stopping by to visit. |
| Pallcare Victoria | www.pallcarevic.asn.au | Lists Victorian Palliative Care Agencies |
| Pallcare Victoria | www.pallcarevic.asn.au/families-patients/about-palliative-care-2/guide-for-carers | Resources for carers and families |
| Service Seeker Community Directories | serviceseeker.com.au/ | Directory of Community Support Services |
| What to do following a death | www.humanservices.gov.au/customer/subjects/what-to-do-following-a-death | Provides information on payments, counselling and financial services to help people adjust to life after someone close to them has died |
| Young Carers | www.youngcarers.net.au/ | This site provides information to help young carers |

LEGAL

| | | |
|---|---|---|
| State Trustees | https://www.statetrustees.com.au/ | State Trustees provides legal and financial services for security and peace of mind. Incl. wills, Powers of Attorney & Executor Services (means tested) |
| Guardianship | www.publicadvocate.vic.gov.au/guardianship-administration/guardianship | Guardianship may be needed if a person is no longer able to make reasonable judgements |
| Office of the Public Advocate | www.publicadvocate.vic.gov.au/ | Matters of financial, legal and lifestyle issues where individuals need assistance or unable to manage their affairs themselves. |
| Take Control | www.publicadvocate.vic.gov.au/our-services/publications-forms/89-take-control?path= | Kit of information produced by the Office of the Public Advocate for making enduring powers of attorney and guardianship. |

FINANCIAL

| | | |
|---|--|--|
| <i>Bereavement Allowance</i> | https://www.humanservices.gov.au/customer/subjects/what-do-following-death | Information regarding counselling and financial services to assist people adjust to life after someone close to them has died. |
| <i>Bereavement Assist</i> | https://www.humanservices.gov.au/customer/services/centrelink/bereavement-payment | Information on easing the adjustment to changed financial circumstances for carers after a death. |
| <i>Carer Allowance</i> | www.humanservices.gov.au/customer/services/centrelink/carers-allowance | Information on an income supplement for carers who provide additional daily care and attention for someone with a disability or medical condition, or who is frail aged.(not means tested) |
| <i>Carer Payment</i> | www.humanservices.gov.au/customer/services/centrelink/carers-payment?utm_id=7 | Information on a payment for people who personally provide constant care, in the home, to someone with a severe disability, medical condition, or who is frail aged. |
| <i>Carers Victoria for financial and practical advice</i> | www.carersvictoria.org.au/ | Carers provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged. |
| <i>Centrelink</i> | www.humanservices.gov.au/customer/dhs/centrelink | Offers financial assistance when income is reduced such as disability, carer, unemployment benefits and health care cards for those on limited incomes. Social workers may also be available to assist |
| <i>Centrepay</i> | www.humanservices.gov.au/customer/services/centrelink/centrelink-centrepay | Information regarding a free and voluntary service to pay bills and expenses as regular deductions from Centrelink payments |
| <i>Concession Cards</i> | www.humanservices.gov.au/customer/subjects/concession-and-health-care-cards | Information on eligibility and how concession and health care cards can help you access cheaper health care services and medicines. |
| <i>Financial Counselling</i> | https://www.moneysmart.gov.au/managing-your-money/managing-debts/financial-counselling | Financial counselling is a free service offered by community organisations, community legal centres and some government agencies. Financial counsellors can help with finance issues |
| <i>Financial Information Service</i> | www.humanservices.gov.au/customer/services/centrelink/financial-information-service | Information on a free, confidential service that provides education and information on financial issues. |
| <i>Help Paying Bills – Cancer Council</i> | www.cancerCouncil.com.au/aboriginalcancer/cancer-information-for-the-community/support-services/help-with-your-bills/ | Information on assistance with utility bills |
| <i>Newstart Allowance</i> | www.humanservices.gov.au/customer/services/centrelink/newstart-allowance | Information on available financial help if looking for work or participating in approved activities that may increase your chances of finding a job. |
| <i>Rent Assistance</i> | www.humanservices.gov.au/customer/services/centrelink/rent-assistance | Information on financial help to people who pay rent and receive a Centrelink payment. |
| <i>The Age Pension</i> | www.humanservices.gov.au/customer/services/centrelink/age-pension | Information on provision of income support and access to a range of concessions for eligible older Australians. |
| <i>Utility Relief Scheme</i> | www.dhs.vic.gov.au/for-individuals/financial-support/concessions/hardship/utility-relief-and-non-mains-utility-grant-scheme | Offers assistance with utility bills in cases of financial hardship. |

INFORMATION/EMOTIONAL AND PSYCHOLOGICAL SUPPORT

| | | |
|--|---|---|
| <i>Canteen</i> | https://www.canteen.org.au/?gclid=Cj0KEQjwiKS3BRUCU-7XQ75Te3NoBEiQAA2t_xE97Z4VfYWApOBz4WyaCwG9QmSKv8jaxxV9QCwkBEaAijs8P8HAQ | Information and resources for 12 – 24 year olds who either have cancer or know someone with cancer. |
| <i>Caresearch</i> | www.caresearch.com.au/caresearch/PatientsCarersAndFamilies/tabid/64/Default.aspx | Online service information for carers |
| <i>Life Circle</i> | www.lifecircle.org.au/ | An organisation of mentor carers who want to help others as a result of their own experience of caring for someone with a life-limiting illness |
| <i>MND Association Victoria</i> | www.mndcare.net.au/End-of-life/The-carer.aspx | Carer resources and information |
| <i>New Hope Migrant Resource Centre - Southern Metro Region</i> | www.newhope.asn.au/contact-us | Migrant resource centre |
| <i>Southern Migrant and Refugee Centre, Narre Warren</i> | www.smrc.org.au/ | Migrant resource centre |
| <i>Supporting a Person Who Needs Palliative Care: A guide for family and friends</i> | centreforpallcare.org/assets/uploads/PCV%20Supporting%20a%20person%20PC%20guide%202012.pdf | Resources for Family Carer Support |
| <i>Talking to Kids About Cancer</i> | www.cancervic.org.au/downloads/brochures/CISS_brochures/Talking-Kids-cancer.pdf | Resources for Family Carer Support |
| <i>The Cancer Council</i> | www.cancervic.org.au/ | Resources for Family Carer Support |

RESPIRE SERVICES

| | | |
|--|---|--|
| <i>Alfred Health Carer Services</i> | www.carersouth.org.au/ | Carer support programs, information; urgent respite, Southern Metro Region |
| <i>My Aged Care Home Care Packages</i> | www.myagedcare.gov.au/aged-care-services/home-care-packages | Information regarding access and services provided by a Home Care Package |
| <i>SMRPCC Respite Brochure</i> | http://www.smrpalliativecare-consortium.org.au/Uploadlibrary/415544638RespiteBrochureSMRPCC_Sep2013.pdf | Respite information for carers in need of a break |

8. Bibliography

- S. Aoun, B. Bentley, L. Funk, C. Toye, G. Grande, & K.D. Stajduhar. *A 10-year literature review of family caregiving for Motor Neurone Disease. Moving from caregiver burden studies to palliative care interventions*. Palliative Medicine, published online 20th August 2012.
- J. K Angelo, R. Egan, K. Reid. *Essential knowledge for family caregivers: a qualitative study*. International Journal of Palliative Nursing 2013, Vol 19, No 8
- F. Burge, B. Lawson, G. Johnston, Y. Asada, P. F. McIntyre, E. Grunfeld & G. Flowerdew. *Bereaved family member perceptions of patient-focused family-centred care during the last 30 days of life using a mortality follow-back survey: does location matter?* BMC Palliative Care 2014, 13:25
- Department of Disability, Housing and Community Services. *A review of carer interventions Appendix B*. ACT Government, September 2003
- C. Finney Lamb & M. M. Smith. *Problems refugees face when accessing health services*. NSW Refugee Health Service, 2000
- G. Ewing, L. Austin, G. Grande. *Challenges to implementing comprehensive carer assessment in palliative home care: findings from a cluster trial*. BMJ Support Palliative Care 2014
- Palliative Care Australia. *The hardest thing I've ever done- the social impact of caring for terminally ill people in Australia*. Canberra, 2004
- *The Victorian Charter supporting people in care relationships*. DHS, July 2012
www.dhs.vic.gov.au/carersact (Available in other languages on request)

9. APPENDIX 1 – Commencing Caring Conversation Checklist

Commencing Caring Conversation Checklist

This checklist is to assist staff to have conversations about commencing caring. The aim is to:

- Provide a baseline of assessment of the carer and their capacity.
- Informed consent around the challenges and difficulties of caring and the possible outcomes.
- Information designed to provide an outline of potential important tasks to be carried out.
- Validating the needs of the carer as separate to the client.
- Ensuring that the carer is introduced to the idea that care can be intermittent and that there are options for care that the carer may take advantage of, and is encouraged to do so.
- Ensuring the carer achieves the goals for the client, reducing poor outcomes.

CARER ROLE

| Topic | Has been covered | Needs follow-up/referral |
|---|------------------|--------------------------|
| Who is able to carry out the main caring role? | | |
| What is this person's current health status? | | |
| How much support can the family and friends provide? | | |
| Do they know that they will be the main carer 24 hours a day with only some visits from health professionals? | | |
| How will this impact on their family? | | |
| Do they need to continue working and caring for dependants? | | |
| What are the challenges for them in continuing their caring role? | | |
| Are there issues of mental health coexisting with the carer or client currently? | | |
| What do they understand about the diagnosis and prognosis? | | |

PLACE OF CARE

| Topic | Has been covered | Needs follow-up/referral |
|--|------------------|--------------------------|
| At home | | |
| What are the implications for the carer? | | |
| What services can be provided by Local Government? | | |
| Community palliative care referrals explained. | | |
| Hospice | | |
| What is a hospice and what services can be expected. | | |
| Hospital | | |
| Under what circumstances would the client be admitted to hospital? | | |
| Respite | | |
| Options explained and contacts made for future uptake of respite. | | |

Practical Considerations Checklist

This checklist is to assist palliative care staff to have conversations about practical issues as well as emotional issues for carers. Clinical tools that can also assist are the Carers assessment tools.eg CSNAT and Bereavement Risk Index.

LEGAL

| Topic | Has been covered | Needs follow-up/referral |
|--|------------------|--------------------------|
| Is there a will | | |
| Enduring Medical Power of Attorney | | |
| Enduring Financial Power of Attorney | | |
| Have they nominated the beneficiaries of their Superannuation? | | |
| Advance Care Plan | | |
| Refusal of Treatment certificate | | |
| If they own their home is it in joint names? | | |

FINANCIAL

| Topic | Has been covered | Needs follow-up/referral |
|--|------------------|--------------------------|
| Has the family got ambulance cover? | | |
| If applicable: mortgage insurance / disability insurance (as part of super?) | | |
| How will their financial situation be impacted upon by current and future circumstances? | | |
| Do they need financial counselling or assistance? | | |
| Are there any grants or funding that they are eligible for? | | |
| How will they manage day to day with income and expenditure? | | |

Emotional/psychological/spiritual/social

| Topic | Has been covered | Needs follow-up/referral |
|--|------------------|--------------------------|
| How is the carer coping? | | |
| What questions do they have about the diagnosis/ prognosis or assistance required? | | |
| Have they been referred to relevant support agencies? Eg, Local government, Allied health, Respite agencies, counselling services, Interpreter services, disease specific support agencies like MNDV, Alzheimer's Australia? | | |
| How will they maintain their links with their spiritual supports? | | |
| How will they maintain their links with their community supports? | | |
| Have younger family members been offered support via their school communities? | | |

