

INTRODUCTION

This Information Support Package has been developed by Neuromuscular WA as a part of the Bereavement Support Program to provide active support for Community in preparation for, and in experiencing bereavement. Some individuals and families benefit from early preparation and having information about services and resources collated in one place to refer to when needed. The Information Support Package is aimed at addressing this and empowering individuals and families to make more informed choices about their future and services they would like to access.

If you would like to talk to us about any of the information in this Support Package, please contact us on 9380 3400.

If any information in the Information Support Package leaves you feeling overwhelmed or distressed, please reach out to Beyond Blue on 1300 22 4636.

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PALLIATIVE CARE

Palliative care is person and family-centred care with the primary aim of optimising quality of life; it extends beyond the end-of-life period. Entering palliative care early can be beneficial, and individuals may move in and out of palliative care services on many occasions throughout their lives to gain support, link to services, or gain access to respite care. It is accessible by anyone with a life-limiting illness, with the aim to help achieve a good quality life. Accessing palliative care can occur simultaneously to receiving treatment and other health care services. Palliative care is conducted by a team of multidisciplinary health professionals, and can involve:

- Management of physical symptoms and pain,
- Emotional, spiritual and psychological support,
- Social care including domestic assistance and provision of personal care,
- Support for families, and to help families discuss sensitive issues,
- Counselling and grief support, and
- Referrals to respite care services.

The following are a list of organisations offering palliative care services in Western Australia you may wish to access.

LION COUNSELLING AND PSYCHOLOGY

Lion Counselling and Psychology offers counselling in the palliative care space for both the individual in palliative care and their family. Additionally, the organisation offers specialised counselling surrounding disability challenges available to family members, carers and support workers to assist with managing their own emotional needs around their care for a person with disability. This service is available in West Perth or can be accessed through Telehealth across the state.

Email: info@lioncounselling.com

Phone: 0401 580 520

Website: www.lioncounselling.com.au

BETHESDA HOSPITAL

Bethesda Hospital offers in-patient palliative care, along with out-patient services and education. Bethesda Hospital's facilities, located in Claremont, offers symptom control care, support for families and loved ones, improving and maintaining quality of life, consultation in decision-making and pastoral care.

Email: palliativenurses@bethesda.org.au

Phone: 08 9340 6311

Website: www.bethesda.org.au/facilities-services/palliative-care/

Information Support Package**WA PAEDIATRIC PALLIATIVE CARE SERVICE**

Specialised for children, WA Paediatric Palliative Care Service's holistic and compassionate care is accessible based out of Perth Children's Hospital. This service offers advice surrounding management of symptoms and acts as a liaison between health providers, community services and children and their families. This enables children to be cared for in the most appropriate place and offers support to children at the end of their life, and their families in bereavement.

Email: Pch.palliativecare@health.wa.gov.au

Phone: 08 6456 2222

Website: www.pch.health.wa.gov.au/our-services/palliative-care

SILVER CHAIN COMMUNITY SPECIALIST PALLIATIVE CARE

Silver Chain Community Specialist Palliative Care program is a palliative care service based in the community with the aim of supporting individuals and their families from the comfort of their own home. This free service can support decision making surrounding treatment, assist in management of symptoms, provide emotional support with social workers and spiritual care workers as a part of their palliative care team.

Website: www.silverchain.org.au/our-services/palliative-care

END OF LIFE PREPARATIONS

There are a number of things that can be prepared to make arrangements easier for your family after your passing.

To ensure all your assets and property are distributed how and to the people you like, it is important to write a will, or revise a previous will. It is best practice to review any will written whenever there is a major life change or significant assets are acquired or lost. Another decision that is important to make known, is your intent to be an organ or tissue donor. This intent can be registered through the government via My Health Records, however your next of kin will have the final say.

Your preferences for your funeral arrangements, or lack thereof, can also be planned and pre-paid for many years prior to your passing. Most funeral companies can facilitate this through directly contacting them. Funeral insurance can also be purchased to reduce the financial pressures on loved ones when the funeral is held.

Advanced Care Plans or Directives are documents detailing your preferences in treatments and health care provision, to assist in decision making when you are unable to communicate your wishes. These can be formally written and uploaded into My Health Records to be accessed by future treating medical professionals using an Advanced Care Directive. Alternatively, an Advanced Care Plan offers a less formalised way of expressing this information.

The following are a list of organisations offering support with end of life preparations in Western Australia you may wish to access.

CARER HELP

Carer Help's website includes information about caring at home, managing symptoms, advance care planning and sorting out financial matters in the preparation for death. Carer Help have developed and run a module titled 'Preparing for Dying' and have a number of factsheets surrounding common experiences, emotions, and services for end-of-life preparations. Additionally, there are a number of videos surrounding preparation for death and after the loss of someone.

Phone: 08 7221 8233

Website: www.carerhelp.com.au

MY VALUES

MyValues is an online resource to assist in decision making on what to include in your advanced care planning, and highlight values with a report produced at the end of the process that can be shared with family or health professionals to guide decision making when you are unable to. Please note, this is not a legally binding document, and medical professionals are not bound to act in the interests of this document. It can be overridden by you at any time verbally, in writing or by revising it.

Website: www.myvalues.org.au

Information Support Package**MY AGED CARE**

My Aged Care has pages dedicated to preparing for end-of-life, end-of-life care, and caring for someone at the end of their life. An extensive list of tips from other carers can be found to both support the person you are caring for and help cope with your own emotions. These include but are not limited to; focus on what you can do, not what you can't, remember sometimes being there is all you need to do, and plan ahead to make it easier to cope through difficult times. For the complete lists, and more information see the My Aged Care website page. On this website, there are also links to the Department of Health and Ages Care, and Carer Gateway resources.

Website: www.myagedcare.gov.au/caring-someone-end-of-life#planning-ahead

PALLIATIVE CARE WA

Palliative Care WA offer multiple forms of support to assist with completing Advanced Care Directives and Advanced Care Plans. A range of community workshops are help in-person and virtually to explain advanced care planning, why it is important and how to access it.

To obtain individualised support with writing or revising your own advanced care plan, a free and confidential service is offered in a one-on-one situation, at a location suitable to you. An experienced professional from Palliative Care WA will assist you to ensure your choices are reflected in your plan.

Phone: 1300 551 704

Website: www.palliativecarewa.asn.au

SERVICE AUSTRALIA

Services Australia has information about what documentation and preparations, including legal documentation, can be made to help honour someone's wishes after their passing. These includes a will to distribute your assets and property, intent to become an organ or tissue donor, and preferences for your funeral or other farewelling service.

Website: www.serviceaustralia.gov.au/what-to-organise-before-you-die?context=60101

DEPARTMENT OF HEALTH

Advanced Care Plans and Advanced Care Directives are important documents in assisting decision making around your preferences in treatments and health care provision, when you are unable to communicate these yourself. The Department of Health has information about what Advanced Care Plans and Directives are, when and how they are used, and how to write your own.

Website: www.health.gov.au/health-topics/palliative-care/planning-your-palliative-care/advance-care-planning#where-to-get-help-support-and-advice

AFTER THE LOSS OF A LOVED ONE

Following the loss of a loved one their passing must be registered with the Australian Government. Depending on the situation, the family may need to lodge an advice of death form or health care professionals may register this for you.

The government offers a number of bereavement supports in the form of allowances and payments that may be accessible depending on your individual circumstances. These include a number of lump sum payments and some allowances that may be able to be accessed, or continued to be accessed following the passing of a loved one for a period of time.

SERVICES AUSTRALIA

The Services Australia website acts as a directory to a number of government websites and supports to assist families when a loved one passes away. This includes information about registration of deaths, organising a funeral, finalising estates and some support services to look after yourself through this process.

Services Australia also offers a number of payments and allowances that may be able to be accessed, or continued to be accessed following the passing of a loved one for a period of time, depending on your unique situation and relationship to the person. Some financial supports that you may be able to access include:

- Carer Allowance
- Pension Bonus Bereavement Payment
- Double Orphan Pension
- Income Support Payment
- ABSTUDY Living Allowance
- Farm Household Allowance
- Carer Payment
- Family Tax Benefit
- Parenting Payment
- JobSeeker Payment
- Youth Allowance

Exceptions to all financial supports apply, and eligibility is dependent on payments being received prior to the persons passing, and the nature of your relationship with your loved one. To ensure you are accessing the correct payments, a Families line can be called to discuss the options applicable to you.

Website: <https://www.servicesaustralia.gov.au/death-loved-one>

Information Support Package**GOVERNMENT OF WESTERN AUSTRALIA**

When someone passes away in a healthcare or aged care setting, the staff members of the facility will make all necessary arrangements for a medical certificate cause of death to be signed. If your loved one passes away at home, please call 000 to reach paramedics, or as you are otherwise advised by your healthcare professionals.

The Registry of Births, Deaths and Marriages must then be notified of someone's passing within 14 days of their funeral, usually by the funeral director. Once registered, the Registry will produce and send a certificate of death.

To access these forms, and for more information about the need and use of death certificates, see the [Apply for a Death Certificate](#) page on Government of Western Australia's website.

Website: <https://www.wa.gov.au/service/justice/civil-law/apply-death-certificate>

COPING WITH SUDDEN LOSS

The loss of a loved one under any circumstances is traumatic, however losing a loved one suddenly presents its own unique difficulties. Although neuromuscular conditions can be life-limiting conditions, one's passing can still be sudden and unexpected, or unrelated to their neuromuscular condition. There are a number of resources available online that can assist with coping in times of sudden loss.

GRIEF STORIES

A Canadian website, Grief Stories, has a video from a therapist's perspective discussing the experience of, and offering some support following sudden loss. The website also contains a blog article titled "When Death Comes Suddenly" detailing someone's experience in sudden loss.

Website: www.griefstories.org

HOPKINS MEDICINE

Another resource is available from Hopkins Medicine, a US medical organisation, that has published online an article from a professional's perspective surrounding numerous forms and expressions of grief, including sudden grief. In addition to this, it discusses anticipatory grief, the stages of grief and ways to provide support to others who are bereaved. This resource breaks these areas down into simple dot points and questions to create direction in early bereavement stages.

Website: www.hopkinsmedicine.org/health/caregiving/grief-and-loss

BANNER HEALTH

Banner Health is a third online resource with an article on navigating grief after a sudden death. This article contains an overview of sudden death with input from professionals in the bereavement space to answer the questions; what the grief process is, what things can help you and your family cope, finding closure, and how can family and friends support them at this time.

Website: www.bannerhealth.com/healthcareblog/better-me/navigating-grief-after-the-traumatic-loss-of-a-loved-one-or-friend

BEREAVEMENT COUNSELLING

Lots of various types of counselling are available, however some organisations offer specific bereavement counselling as a speciality placing them in the best position to support individuals and families who are experiencing bereavement.

Neuromuscular WA offers a number of free counselling sessions with MSWA's counsellors that can be accessed at any point in your condition journey. This MSWA service is not a crisis service meaning there may be a wait period of several weeks before your appointment can be held, and this counselling is not specifically bereavement counselling. To access this service, please contact us at info@neuromuscularwa.org.au or 08 9380 3400.

Neuromuscular WA also have a connection to a bereavement counselling service. This is based in the South-West and therefore conducted primarily via video conferences or phone calls, however the South West Grief and Loss Centre do facilitate face-to-face in person counselling for those reside locally. To access this service, please contact Neuromuscular WA at info@neuromuscularwa.org.au or 08 9380 3400.

Although this is the service Neuromuscular WA offers, there are additional alternate options available publicly listed below.

THE GRIEF CENTRE OF WA

The Grief Centre of WA offers counselling for any type of grief or loss delivered either in person at their Tuart Hill location, or via video call or phone call. The Grief Centre offers counselling for all forms of grief, but counsellors additionally have experience and training in bereavement counselling specifically. This organisation has counsellors qualified in a variety of fields, enabling them to offer sessions of compassionate listening, sand-play and art therapy, and Cognitive Behavioural Therapy. Counsellors can style sessions for adults, teenagers and children who are grieving, as well as facilitate family and couple sessions.

Phone: 0404 658 052

Website: www.griefcentrewa.org.au

LIFELINE WA

If in person counselling is your preference, Lifeline WA offers in person counselling in Perth, or counselling sessions via phone call and video call with up to 6 sessions free to families and children for loss or grief, regardless of how much time has passed since the loss.

Phone: 08 9261 4444

Email: reception@lifeline.wa.org.au

Website: www.lifelinewa.org.au

Information Support Package**THE RED NOSE: GRIEF AND LOSS FOUNDATION**

The Red Nose: Grief and Loss Foundation offer a range of services targeted at families of those who have lost an infant or child/children under 12 years. This organisation supports a national 24hr free call support line available for use of parents, family, friends or peers at 1300 308 307. In addition to this support line, Red Nose: Grief and Loss offer a counselling service facilitated over the phone.

Phone: 1300 308 307 (24/7 support line)

Email: support@rednose.org.au

Website: www.rednosegriefandloss.org.au

GRIEFLINE

Griefline offer two toll-free help lines. A national helpline that operates 7 days a week between 6am and midnight AEST can be reached at 1300 845 745. An additional state helpline is available for toll-free calls 7 days a week between 6am and midnight local time at 08 6244 8196. By calling this service, Griefline's trained and experienced volunteers offer confidential phone counselling support for anyone who is experiencing grief, loss, trauma, loneliness or isolation.

Phone: 1300 845 745 (national helpline), 08 6244 8196 (state helpline)

Website: www.griefline.org.au

SUPPORT GROUPS

General support groups that are non-specific to the reason for grief are available through a number of organisations. Support groups offer a safe environment to talk about, share and listen to others who all have shared similar experience. This offers an opportunity to connect with others who better understand what you are experiencing, and offer mutual support to each other during challenging times. Some support groups undertake an activity such as a walk or camp, while others meet on occasion simply to talk.

Some support groups available in Western Australia that you may wish to consider are listed below.

THE GRIEF CENTRE OF WA

The Grief Centre of WA offers several support groups across Tuesdays and Wednesdays, including one youth-specific bereavement group, life after loss groups and a waves of grief support group. In addition to these support groups, the Grief Centre of WA also hold community grief gatherings and creative and therapeutic workshops. These include; community grief gatherings, meditation journeys, walks and writing workshops.

Phone: 0404 658 052

Website: www.griefcentrewa.org.au

SOLACE WA

Solace WA is targeted at an older population grieving a partner and has a number of trained facilitators and support workers in their team. Solace WA offer a number of support groups in-person for walking groups, gender specific café and lunch meetings, and sharing and caring support groups, in addition to online zoom support meetings to allow the broader WA area to access supports. Surrounding their support groups, Solace WA also offer 24 hour a day telephone support.

Phone: 0488 991 084

Email: info@solacegriefsupport.wa.org.au

Website: www.solacegriefsupportwa.org.au

LIONHEART CAMP FOR KIDS

Lionheart Camp for Kids aims to strengthen families connections, and teach skills to navigate life and reimagine grief as a natural, healthy and normal response. Lionheart offers camps separated into age groups, as well as offering Lionheart Lounge; an online support program run on a weekly basis. All Lionheart Camp for Kids programs are specifically aimed to support children following the death of a parent, primary caregiver or sibling, and are offered as free services.

Email: enquiries@lionheartcampforkids.com.au

Website: www.lionheartcampforkids.com.au

Information Support Package**THE RED NOSE: GRIEF AND LOSS**

The Red Nose: Grief and Loss offer a differing form of peer support digitally. This organisation has a live chat with peer supporters available from 10am to 3pm on Mondays, Wednesdays and Fridays. More traditional support groups are also available, one face-to-face held in Kensington, others available online separated into groups based on the reason for seeking support. Each of these run monthly meetings, are free to access with registration via the Red Nose: Grief and Loss website.

Phone: 1300 308 307 (24/7 support line)

Email: support@rednose.org.au

Website: www.rednosegriefandloss.org.au

GRIEFLINE

Griefline hosts online moderated forums through their website to allow support to be gained from peers. These forums are safe spaces, accessible only by members of the online community and supported by trained volunteers. Griefline offers forums with differing focuses; loss of a loved one, sharing of helpful resources in grief, and support for loneliness and isolation.

Phone: 1300 845 745 (national helpline), 08 6244 8196 (state helpline)

Website: www.griefline.org.au

DEATH CAFÉ

Death Café's are group directed discussions of death, that are aimed at creating a safe space to discuss death, experiences and how to make the most of your finite life, rather than a counselling styled session or traditional support group. Often these are not facilitated by any professionals in the bereavement space and can be run for specialised groups or open to anyone at a variety of locations. A list of upcoming cafes can be found on their website.

Website: www.deathcafe.com

Information Support Package**SHARED STORIES**

Reading and hearing stories and experiences of others who have been or are going through a similar experience to yourself, can provide comfort and reduce the feeling of isolation, as well as validate your own feelings and responses. Some organisations provide the opportunity for people to publicly share their stories with the world, for others to find online and gain support from.

GRIEFLINE

Griefline monitors online forums in which members can share experiences, advise, hardships and connect with each other and resources. Two of these forums include 'Loss of a Loved One' for discussion from people dealing with the loss of a partner, family member or close friend, and 'Helping Hand' creating a space to share grief and loss recourses including helpful support groups, books, films and television programs.

Website: <https://griefline.org.au>

GRIEF STORIES

Grief Stories is a Canadian organisation that collates and makes accessible griever insights and stories to share with others with the aim to reduce feelings of loneliness. Their website contains videos and blog writings with shared stories of loss and numerous aspects of grief. There are pages of blogs and videos with personal accounts and experiences available for viewing on the website, ranging from a variety of point of views and surrounding many types of losses.

Website: <https://www.griefstories.org/>

HONOURING A LOVED ONE

There are endless ways one can remember and honour their lost loved one, and many find the most meaningful way personal to their loved one and the life they led. Some common suggestions of ways to honour a passed loved one include:

- Creating a piece of jewellery customised with their handwriting, containing their ashes or a piece of their hair, or engraved with their initials and date of death
- Framing an item of theirs or piece of their writing; this could include framing a postcard from them or their favourite watch
- Saving a seat for the loved one at important events or family gatherings for a period of time following their passing
- Mark a space in their honour; a bench at a park they loved, a brick in the families backyard or another meaningful location with their initials or name
- Create a living memorial by planting a tree at a meaningful place or begin a garden with their favourite flowers or foods
- Complete something they could not. If there is a project or role they hadn't finished before passing, completing it on their behalf is a meaningful way of connecting to what mattered to them
- Attempt an item on their bucket list or their favourite activity in their memory. This could become an annual event all those who loved them engage in as a memorial to them
- Advocate or involve yourself in a cause that was important to your loved one, or that relates to their death
- Prepare their favourite meal and share the recipe with their name included in the title
- Repurpose some of their items or clothes into a piece of art, jewellery, or quilt that you can continue to use and keep with you
- Create a playlist of their favourite songs to listen to and play at family gatherings
- Talk about them, share stories with other who knew them, and collect memories to write down and store in a memory jar

The following are a number of organisations that offer a way or space to honour a loved one.

RED NOSE GRIEF AND LOSS

Red Nose Grief and Loss created a space to remember lost children on their memory wall. Loved one's are able to submit a memory with their child's name, birth and death date, photo if they would like and write a message. As the Red Nose foundation is an organisation for supporting families of babies and young children who have passed, this space is also only for remembering young children.

Website: www.rednosegriefandloss.org.au

Information Support Package**THE COMPASSIONATE FRIENDS**

The Compassionate Friends host a similar Memorial Page on their website where a loved one may opt to upload a photo, name, date of birth and death, and write a message about the person who passed. Information about the Kings Park's Botanic Garden's contemplative space known as the Place of Reflection can also be found on The Compassionate Friends website.

Website: www.compassionatefriendswa.org.au

THE COMPASSIONATE FRIENDS VICTORIA

In Loving Memory is a space The Compassionate Friends Victoria have created to commemorate a lost child, sibling or loved one. One can add their own memory to the digital book with their loved one's name, age, date of birth and death, and a message or memory of them.

Website: <https://www.compassionatefriendsvictoria.org.au>

RESOURCES AND COMMUNITY EDUCATION

A number of organisations have developed informative resources surrounding the grief and bereavement space. These include downloadable information sheets, booklets, articles written by professionals in their fields, blogs and videos. The following are a number of organisations with publicly available resources you may wish to view.

THE AUSTRALIAN CENTRE FOR GRIEF AND BEREAVEMENT

The Australian Centre for Grief and Bereavement (ACGB), who developed information sheets available via for download or hardcopy order, surrounding the topics of general grief, supporting others who are grieving, grief through different ages, and bereavement in the workplace. The ACGB additionally developed a booklet titled 'After the Loss of a Child: a resource for parents of children in palliative care'. This includes details on seeking help and resources, grief over time, parenting after the loss of a child, grief and relationships, before the death and after the death.

Website: www.grief.org.au

CARER HELP

Carer Help is an organisation focused primarily on end-of-life caring and post-caring life, offering factsheets and videos for preparation for death and after the loss of someone. They offer a range of resources and modules ordered in the following Carer Pathways:

1. When someone needs care
2. Caring when death is a possibility
3. Preparing for dying
4. When the person is dying
5. After caring

Each pathway includes a downloadable resource, video/s, helpline numbers, and other resources/networks that can be linked into to gain more support.

Website: <https://www.carerhelp.com.au>

THE RED NOSE: GRIEF AND LOSS FOUNDATION

The Red Nose: Grief and Loss Foundation has a library of articles and writings on personal testimonies, support services and experiences available on their website. These articles are classified into groups targeted at fathers, mothers and all loved ones, with some as written articles and others in video formats.

Website: www.rednosegriefandloss.org.au

Information Support Package**MY GREIF ASSIST**

Another accessible resource hub is offered by My Greif Assist. This organisation's website contains simple factsheets, grief inspiration and resources including some book, movie and music recommendations. A library of downloadable factsheets written by experts are available as well as informative videos on topics including the value of funerals, gratitude thinking and grief, parents' grief, and children experiencing bereavement. My Grief Assist's resources are easy to read or view and provide a good early support for recent grief.

Website: www.mygriefassist.com.au

THE COMPASSIONATE FRIENDS VICTORIA

The Compassionate Friends Victoria (T.C.F.V.), although not offering services in WA has numerous resource sheets, videos and a blog that are accessible and helpful. This organisation has information for all loved ones, but places a focus on support for bereaved siblings, offering advice about healing processes, practical forms of coping, rethinking closure, and commonalities and differences in grief. T.C.F.V. offers resources in video format as well including one video that addresses the myths of grief. A number of research materials are available written by professionals or academics on a variety of topics.

Website: <https://www.compassionatefriendsvictoria.org.au>

GRIEFLINE

The Griefline website has numerous grief and loss resources including evidence-based articles in a range of areas. These easy-to-read resources include topics of loneliness, isolation, delayed grief, grief in children, understanding trauma and experiences of grief, and supporting a grieving friend. In addition to bereavement resources, there are also resources with guidance for self-care and wellbeing through times of any type of grief, stressful or traumatic events and isolation.

Website: <https://griefline.org.au>

GRIEF STORIES

Grief Stories is an organisation with writings, articles and videos about coping and healing methods. These include art, music and therapeutic writing for healing, with videos of professionals detailing the benefits these have in bereavement and grief. Included among these, is a grief educators blog post about grief and disability.

Website: www.griefstories.org

Information Support Package**GOOD GREIF**

The organisation Good Greif has published a number of factsheets for different age groups dealing with grief and loss. These include ones about how to support yourself and others from varying age groups ranging from children to adults. In addition to these, there is a series of programs available on coping methods, including 'Seasons for Growth' aimed at strengthening the social and emotional wellbeing, and a 'Seasons for Healing' program for Aboriginal and Torres Strait Islander people in culturally appropriate ways to learn of grief, loss and change.

Website: www.goodgrief.org.au/grief-resources

THE GRIEF CENTRE NEW ZEALAND

The Grief Centre New Zealand has a range of booklets downloadable on their website for loss of different relationships, sudden loss, supporting children through bereavement, and post traumatic growth after grief. Additionally, a community resource library of videos are published on the Grief Centre of New Zealand's Facebook page. These videos range in length between very short and more than an hour, each focused on a different topic. Links to this library are throughout their website.

Website: www.griefcentre.org.nz