

# Palliative Care in Aged Care

## A Guide for Families



MCM Palliative Care Services would like to thank those who contributed their experiences and assisted us in developing a resource that would support families and friends of people dying in aged care homes.

MCM acknowledges the Traditional Owners of the waterways and lands where we work. We pay our respects to Elders past and present. We are committed to ensuring everyone we work with is safe, empowered, supported and respected. We support and celebrate diversity of race, culture, ability, age, gender, sexuality and gender identity.

The Palliative Care in Aged Care, A Guide for Families resource has been funded by the Commonwealth Department of Health and Ageing and the Victorian Department of Health as part of the Comprehensive Palliative Care in Aged Care Measure.

**Contact  
MCM Palliative Care**

8.30am – 4.30pm  
Monday – Friday  
03 9977 0026

**Interpreting Service**

Call 13 14 50 and  
Quote Access Code  
99770026

This project is supported by funding from the Australian Government under the Department of Health and Aged Care and the Victorian State Government Department of Health as part of the Comprehensive Palliative Care in Aged Care Project.



**Contents**

Melbourne City Mission Palliative Care	04
Our Team	05
Information resource for families	06
Understanding Palliative Care	08
Good days and bad	09
The last days and weeks	09
The process of dying: A guide for carers & families	10
Pain	11
Increased fatigue/weakness	12
Breathing	12
Swallowing difficulties / not eating or drinking	13
Secretions (noisy breathing)	13
Confusion	15
Incontinence	15
Restlessness	16
Temperature	16
Emotional changes as death approaches	17
Looking after yourself	18
Grief & Bereavement Support	19
Frequently Asked Questions	20
Links and Support	22
Your Information and Privacy	23
Your feedback is important to us	28

## MCM Palliative Care

Melbourne City Mission (MCM) provides specialised palliative care services to people living in aged care homes within the Northwest region of Melbourne.

Palliative care services are available to support people with all forms of end-of-life conditions, such as chronic illness, cancer, dementia, and acute illness.

Our approach is led by our specialised nursing and allied care staff who work in collaboration with families, the aged care home staff, GP's, & other services involved with the care of your family member.

Our team is an additional support to the existing primary care team already in place for the resident. The oversight of each person's care will remain with the Aged Care staff and GP.

### MCM Palliative Care Services

**Residential in-reach Services** (hospital)

**Hospital in the Home**

**Geriatrician**

**Allied Health Services**

**Aged Care Staff**

**Virtual Emergency Department**

**GP**

**Other Specialist Services**

RESIDENT FAMILY →

PRIMARY CARE TEAM →

ADDITIONAL SUPPORTS



## Our Aged Care Team

The Aged Care Team is a specialist palliative care consult team staffed by Clinical Nurse Consultants and Allied Care.

“The way we work is collaborative, respectful & client-centre, recognising that spirituality is woven into all aspects of who we are, including our relationships with self, family, friends and others. Our goal is to support your unique needs in individualised and empowering ways.

We acknowledge each person's country, beliefs, values, wishes, experience, history and culture. Our clients, their families, and carers are at the heart of our work, and we are here to support you at this time.”

— MCM PC Staff Member

Our goal is to support the person, their family or their medical treatment decision maker, and their aged care home to promote:

**Early care planning to avoid unnecessary hospitalisations and ensure that your family member's wishes and preferences are known and respected.**

**Improved symptom management and comfort care.**

**Family support and counselling.**

**End-of-life occurring within the aged care home.**

Additional support from the wider MCM Palliative Care Team (MCMPC) is available for:

**24/7 clinical phone support**

**A palliative care doctor for advice on complex symptom management**

**Ongoing bereavement counselling**

Often the most valuable role palliative care specialists play is supporting other healthcare teams and professionals through consultation, advice and support to provide end-of-life care to residents.



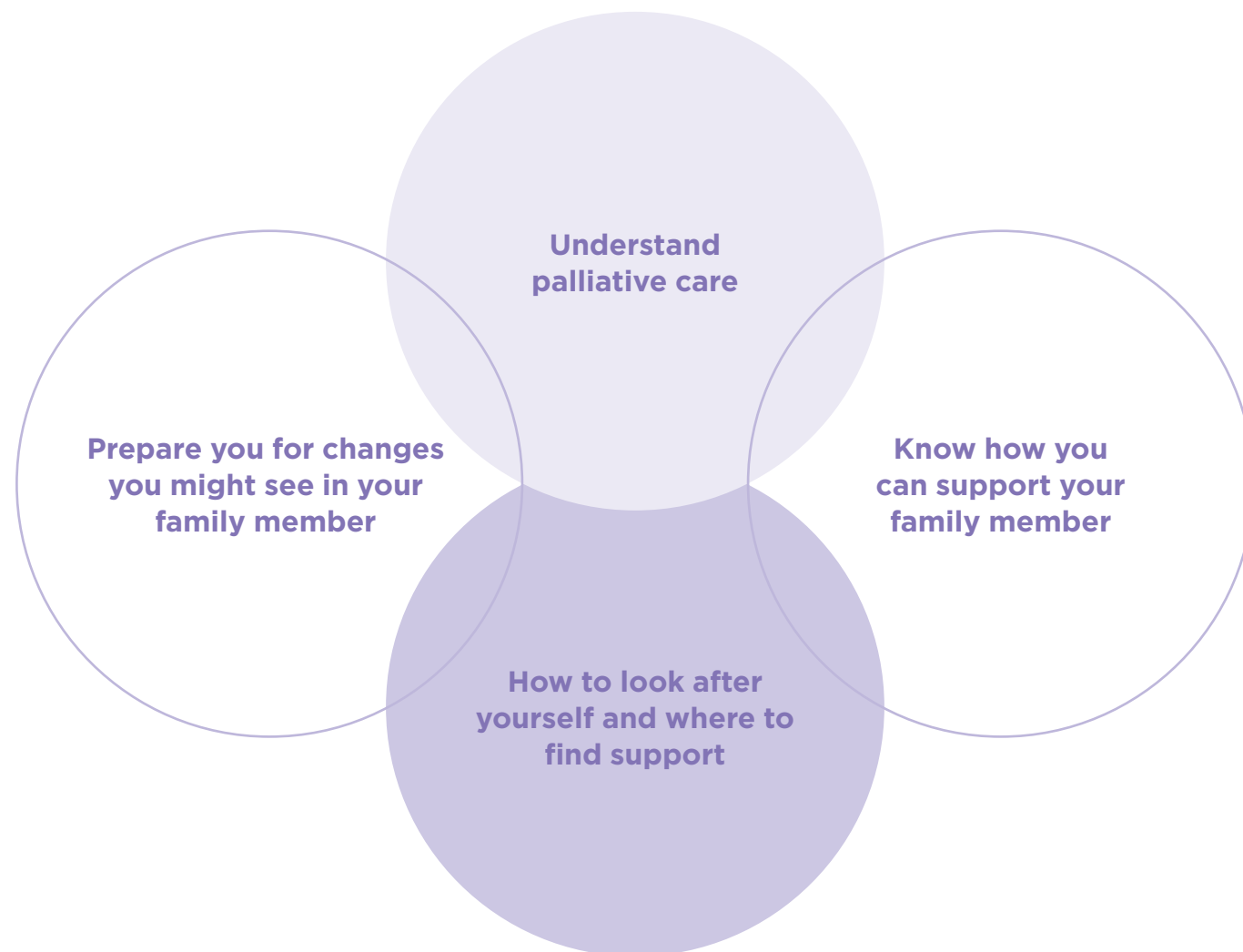
## Information resource for families

Admission to an aged care home is usually marked by a decline in health and the functions of daily life.

The length of time a person will live in an aged care home varies. However, end of life is likely to occur within the aged care home for most residents.

This information resource aims to support residents' families and significant others with their understanding of palliative care and working with the MCM Palliative Care Team.

The information in this resource aims to help you:



“Having the Palliative Care Team involved means we have support 24/7. If we have any concerns we can just call which is invaluable.”

— Aged Care Staff Member



## Understanding Palliative Care

Palliative care is an approach that improves the quality of life for residents who are facing a life-limiting illness and their families.

It prevents and relieves distress through the early identification, correct assessment and treatment of pain and other concerns, whether physical, psychosocial, or spiritual.

Palliative care is based on a person's needs rather than their diagnosis or possible time to death. Palliative care is different for everyone, and your family member's needs and wants may change significantly through the stages of their illness.

It is important to ensure that both the MCM Palliative Care Team and the aged care team are fully aware of your family member's values, preferences and your preferred role during this process. Understanding the goals of care and making medical treatment decisions can feel overwhelming. Being prepared will help.

Leaving difficult conversations and decision making to the last minute may often result in unnecessary treatments or hospitalisations that can be distressing for all.

You can find more information at [Dignified and Respectful Decisions from Palliative Care Victoria](#).

“MCMPC helped me understand the processes. They guided me about outcomes and consequences.”

— Family Voice



## Good Days and Bad

Approaching the end of life (end of life may be referred to as the last year of life) can come with good days and bad days. Some days your family member may be able to eat, drink, be out of bed, and interact with others.

Other days may be quite different, but this is still considered normal. Your family member may not want to eat or drink. Having a shower and being out of bed may be too much. They may not have the energy to interact with you or others.

Regular conversations with the staff at the aged care home and MCM Palliative Care Team can help you understand and make sense of the good days and the bad.

The staff at the aged care home provide 24/7 support and care to your family member. They will regularly monitor for any changes in symptoms that may require changes to the care and support being provided.

## The Last Days and Weeks

As your family member approaches the final days to weeks of life, known as the terminal phase of palliative care, this can become a distressing time for families and friends. The aged care home staff will continue to regularly assess the needs of your family member. This is the time when your family member will:

---

Sleep more,

---

Remain in bed for longer,

---

Eat and drink less or not at all,

---

Interact less or not at all,

---

May appear more restless or agitated

The goal of care is for your family member to be as comfortable as possible, physically and emotionally.

“MCMPC supported me, very well. Overall, my experience with palliative care was positive, and my man was shown full respect and dignity”

— Family Voice



## The Process of Dying A Guide for Carers and Families

The process of dying and a person's death are uniquely individual experiences. However, people in the advanced stage of a terminal illness experience similar symptoms as they approach the end of life, regardless of their illness. The following information may answer questions or concerns you have about what will happen to your family member as death approaches.

## Pain

Pain is a distressing symptom that can be both physical and psychological in nature.

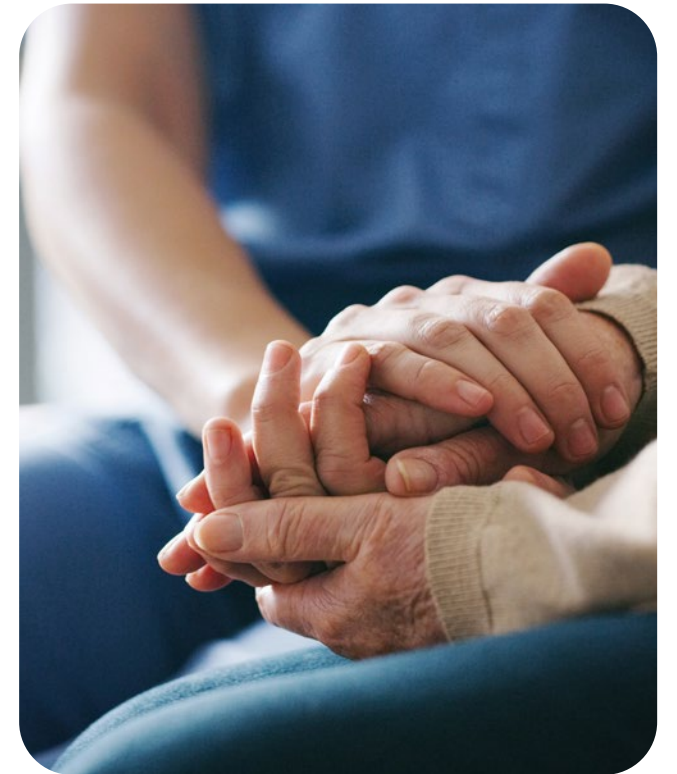
It is individual, meaning that most people do not experience the same type of pain nor demonstrate the same signs of pain.

What is tolerable for one person may not be for another. Untreated pain can cause or increase tiredness, low mood, poor appetite, fear and agitation.

The aged care home clinical staff will assess pain regularly. Their assessment will guide and determine when the use of pain medications is appropriate.

You know your family member best. Recognising and informing the palliative care team and the aged care home team about the unique signs of pain or distress that you observe in your family member is important. This information will assist the team to plan the best possible care.

The palliative team, GP or other specialist will work with the aged care home clinical staff to ensure pain is controlled and your family member is as comfortable as possible. We focus on prevention and early intervention to manage pain.



“Understanding pain management, managing side effects with the different medications, what to expect and knowing you were there! You were wonderful and I thank you!”

— Family Voice



## Increased fatigue or weakness

### What you may see

Your family member will gradually spend more time sleeping and may be difficult to wake at times. Increased sleeping, progressing to increasing periods of unconsciousness, is a change in the body due to the dying process.

You will notice that aged care home staff will need to assist your family member with physical and personal care. Eventually all care will be managed in bed.

### What you can do

- \* Understanding and being supportive of this change is the best way you can help.
- \* Call staff if you see signs that your family member is experiencing any discomfort.
- \* Do not assume that your family member cannot hear what is being said. Gentle words, hand holding, soft lighting, music.



## Breathing

### What you may see

Significant changes in breathing patterns occur during the dying process. Sometimes the breathing may be shallow and rapid and at other times there may be long gaps between breaths. Breathing may also become noisy and appear laboured.

Aged care home staff will position your family member for maximum comfort.

### What you can do

- \* If required, the MCM palliative care team can show aged care staff and family how to do this. It is important to know that this breathing is not distressing to the person.



## Swallowing Difficulties or Not Eating / Drinking

### What you may see

Your family member will eventually not want, and will be unable, to eat and drink normally. Inability to swallow is caused by the weakening of the swallowing reflex and is a natural part of the dying process.

### What you can do

- \* It may be possible to offer small sips of water from a teaspoon, gently dry any spills.
- \* Moist mouth swabs or tiny amounts of crushed ice will help relieve feelings of mouth dryness.
- \* A lip balm will help prevent lips cracking.
- \* Be aware that forcing food or fluids may cause distress – both for the person and the family member.



## Secretions (noisy breathing)

### What you may see

As coughing and swallowing reflexes diminish, saliva and mucous may collect in the back of their throat. This causes a gurgling sound which can be upsetting for family members but is usually not distressing for the person you care about.

### What you can do

- \* The aged care home staff will position them to allow the secretions to drain. MCMPC can show aged care staff and families how to do this.
- \* Sometimes medications can be given to slow down the production of secretions and thus improve comfort.
- \* These secretions can sometimes be brownish – do not be alarmed.



“I was provided with greater explanation/in depth conversation of what ‘palliative care’ means and why someone is in palliative care. I needed time to digest this and understand what is to come with time.

Overall, what was provided was an excellent and invaluable service. Having you available gave me the support then and now to get through difficult situations.”

— Family Voice



## Confusion

### What you may see

Your family member may become increasingly confused about their surroundings, and even who you are. The level of awareness can change often and unexpectedly. Sometimes the person may hear voices or see visions.

### What you can do

- \* Talk calmly with your family member. Do not argue with them or try to orient them to reality. Talk about familiar things, hobbies, family, and cherished times. Show and talk about special photos. It doesn't matter if they cannot answer.
- \* When assisting your family member, explain what you are doing. Don't assume they cannot hear you.
- \* Try playing calm pieces of music and ensure room temperature and lighting are comforting.



## Restlessness

### What you may see

Due to the changes happening in the body during the dying process, some people become restless and even fearful. They may call out, groan, muscles may twitch, and they may be agitated.

### What you can do

- \* Speak quietly and calmly to them, provide reassurance. Try a position change (with help from staff) or gentle hand / foot massage.
- \* Gentle music, aromatherapy, controlled lighting and temperature, or provide a favourite object such as a cozy blanket.
- \* If necessary, the aged care home staff may administer medications.





## Incontinence

### What you may see

As they get weaker, the muscles of the bowel and bladder may relax and incontinence or involuntary loss of urine or faeces may occur. The amount of urine produced and the need to use the bowels decreases during the dying process.

Incontinence care and suitable products should be provided by the aged care home with the necessary care attended by the clinical staff. Sometimes the person may experience the need to pass urine but is unable to, which can lead to restlessness and agitation.

### What you can do

- \* Watch for signs of incontinence and report to care staff if you see signs of restlessness or smell an odour.
- \* If your family member seems embarrassed or distressed, reassure them.



## Temperature

### What you may see

Due to the dying process the body's ability to regulate its temperature begins to fail. Your family member may kick off the bed clothes but be cold to the touch.

It is common for hands and feet to feel cooler than the rest of the body and sometimes parts of the person's body become blotchy or darker in colour.

### What you can do

- \* If they seem cold, light bedding can be used to keep them warm.
- \* A fan to circulate the air and cool, damp towels can help if they seem hot.
- \* Check for damp clothing which would be uncomfortable.



## Emotional Changes as Death Approaches

### What you may see

As death approaches, the person may become less interested in the outside world and the specific details of daily life. They may turn more inward and be less socially involved with others. They may want only a few people to be close to them. They may remember events from long ago in vivid detail but not remember what happened an hour ago.

They may talk about seeing or hearing others who have died before them and you may hear them talking with a dead friend or relative. They may express awareness of their dying and sometimes fear.

### What you can do

- \* If possible, try not to become frightened or upset if you see this happening. Sit with the person and simply "be" with them.
- \* Validate their feelings, do not deny that death is imminent. Gentle talking, holding hands.
- \* If appropriate, make sure that anybody who wishes to see the person before they die has the opportunity to do so.
- \* Where appropriate discuss with the aged care home staff to ensure your family member's spiritual preferences related to dying are respected.



## Looking after yourself

Looking after yourself whilst caring for someone you love at the end of their life is never easy.

While you are prioritising your family member's needs, it is important to take care of yourself too. Otherwise, it's easy to become physically and emotionally exhausted.

Decide how much you wish to be with your family member during this time and advise aged care home team. It is often possible to provide a comfortable chair and blankets for you to rest.

**And remember - while it can feel like you aren't helping at all, hearing is one of the last senses to go before death.**

**So, keep talking, or play familiar music. You are making a difference just by 'being'.**



### Good nutrition and hydration

Try to eat regularly. Get a proper meal when you can. Drinking water is important. If we are not well hydrated our brains don't work as well.



### Take a break

It's easy to underestimate how tiring it is to be constantly at the bedside. Take a walk or sit in the garden. Even a brief change of scenery can be refreshing.



### It's good to talk

If you don't want to burden other family members with your feelings, talk to someone who isn't directly involved. You can be more open about how you feel.

## Grief and Bereavement Support

**"The grief counsellor was very helpful and caring. They gave me lots of kind and helpful advice"**

— Family Voice



Grief is our response to the death of a loved one. It is a normal, natural and inevitable response to loss. Grief can affect every part of our life, including our thoughts, behaviours, beliefs, feelings, physical health and our relationships with others.

Many people are shocked by the death of a family member, even when our loved one was older and death was expected. Everyone grieves differently, and there is no correct way of grieving. It can be exhausting and emotionally draining, making it hard to do simple things or even leave the house.

Most people find that grief lessens with time. A person who loses a loved one may always carry sadness and miss the person who has died, but they are able to find meaning and experience pleasure again. Some people even find new wisdom and strength after experiences of loss.

With the support of family and friends, many people adapt to loss well and may not experience intense and persistent feelings. However, for some, the experience of grief can be overwhelming and further support may be helpful.

Grief and bereavement support, as well as advocacy, are available to all families and carers of loved ones who have been on our program. This may be through counselling in our offices, at your home, via video link, on the telephone or a place of your choosing. We also run information and support groups.



## Frequently Asked Questions

### How does palliative care differ from the current care my family member receives?

Palliative care acknowledges there is a life-limiting illness and the inevitability of death. Staff are guided by your family member's changing needs on a day-to-day basis. The focus is to relieve discomfort for your family member.

### What can I do to help my family member?

Understanding their illness and symptoms and ensuring clear communication with the aged care home staff will help you know what to do. There are also tips provided in this handbook of things you can do depending on their symptoms.

### Can my family member receive palliative care in their aged care home?

Yes, palliative care can be provided in the aged care home. Our specialised palliative care team is here to support the aged care home team as well as your family member and you.

### My family member has stopped eating and drinking will they die of starvation?

As illness progresses it is common not to feel hungry and thirsty. Death will occur due to their illness, not starvation.

### Does morphine or similar medications make death occur faster?

Morphine or similar palliative medications are used to treat pain and keep your family member comfortable. Morphine and similar medications do not hasten death.

### Is it preferable and / or always possible for residents to die in their aged care home?

Usually, a person will be able to be supported and given holistic care to enable them to die at their aged care home. However, in some circumstances where the person's illness is extremely complex, it may become necessary for the person to be transferred to a hospital or in-patient palliative care service. Your family member's wishes and your preferences should be communicated to aged care home team or staff.

### What happens after my family member dies?

If you are not present, you will be contacted by the aged care home and be able to visit. Aged care nursing staff will complete a verification of death. When you are ready, your chosen funeral director will then transfer your loved one into their care. The GP is required to complete a death certificate before the funeral.

### Who should I speak to if I have concerns about the day-to-day care my family member is receiving?

The aged care home is primarily responsible for the day-to-day care of your family member. If you have concerns about care, we encourage you to speak with the staff at the aged care home. When you feel you need additional support or information about the palliative care plan for your family member you can contact the MCM Palliative Care Team.

### What do I do about funeral arrangements?

Taking time to discuss funeral preferences with your loved one ensures that the decisions made are reflective and honoring of the individual while also balancing family needs. You will need to provide the name of your preferred Funeral Director to the aged care home. **Gathered Here** can assist with finding a suitable service. The more specific details about a funeral can wait and the Funeral Director will guide you and your family through these.

## Support & Resources

### Elders Rights Advocacy

1800 700 600  
[elderrights.org.au](http://elderrights.org.au)

Elder Rights Advocacy promotes the human rights of all older Victorians to receive safe, quality aged care. Our contact number is free, confidential and independent.

### Australian Centre for Grief and Bereavement

[grief.org.au](http://grief.org.au)

Includes details of a free bereavement counselling service, links to other grief related websites.

### 10 Questions

[10questions.org.au](http://10questions.org.au)

10 Questions to ask leaflets aim to make your journey easier – Including '10 Questions to ask about Palliative Care in Residential Aged Care'.

### Palliative Care Victoria

(03) 9662 9644  
[pallcarevic.asn.au](http://pallcarevic.asn.au)

Palliative Care Victoria provides information to families and individuals about palliative care and empowers and supports them to enhance the quality of life for the loved one they care for. There is information for Aboriginal people and Torres Strait Islanders, and resources are available in different languages.

### Aged Care Complaints, Quality and Safety Commission

1800 951 822

General complaints and concerns regarding the care and services you receive from your aged care provider.

### Gathered Here

1800 572 130  
[gatheredhere.com.au](http://gatheredhere.com.au)

Gathered Here provides information on a range of end-of-life matters including making a will and planning a funeral.

### Griefline

1300 845 745  
[griefline.org.au](http://griefline.org.au)

GriefLine is a national not-for-profit organisation that provides free telephone support, online bereavement support groups and forums, grief resources and information and education and training programs. You can call their Helpline on Monday to Friday from 8am to 8pm.

### Australian Death Notification Service

[deathnotification.gov.au](http://deathnotification.gov.au)

A free government initiative to help people get in touch with multiple organisations using a single online notification.

## Your Information and Privacy

It is important that you read MCM's Privacy Policy, which you can find at [mcm.org.au/your-privacy](http://mcm.org.au/your-privacy).

We will ensure your privacy is protected and treated with the utmost care. In some cases MCM may need to share your personal information with external service providers. We will only do this if: you or another person is at serious and imminent risk of harm, or it is required in accordance with the palliative care consent form. It is required or permitted by law (such as by a court order or an Act, child abuse concerns or the Family Violence Information Sharing and Child Information Sharing Legislation).

## Your feedback is important

MCM take all complaints, compliments and general feedback seriously. We see it as an opportunity to improve our services.

Complaints, compliments and feedback are accepted at MCM via a range of methods. People providing feedback will be responded to irrespective of how it is provided.

For more Information about MCM palliative care, scan the QR code below.







# Palliative Care

## **Contact** **MCM Palliative Care**

8.30am - 4.30pm  
Monday - Friday  
03 9977 0026

## **Interpreting Service**

Call 13 14 50 and  
Quote Access Code  
99770026