leukaemia & blood cancer
NEW ZEALAND
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OPTIONS FOR END-OF-LIFE CARE

An information sheet for patients, families and whānau

As your condition changes, so might your needs. It is worth considering what your options are and what is important for you and your whānau. This document provides information on palliative care and the support available to live at home, residential care facilities and hospice services.

There are many misconceptions about hospices and palliative care. In reality, most patients and family/whānau find that their comfort and quality of life are enhanced with palliative care.

WHAT IS PALLIATIVE CARE?

Palliative care supports people with a life-limiting illness to live as comfortably as they can. It focuses on improving quality of life and well-being by treating symptoms and supporting patients and whānau with psychological, social, spiritual and cultural needs. Various health professionals provide palliative care, including GPs, district nurses, residential care facilities, specialist hospital-based teams and hospices. Most patients receive palliative care in their homes through hospice community teams. Palliative care can be long term, not just end-of-life care.

What are hospices?

Hospices are services that specialise in palliative care. This includes physical, emotional, spiritual, psychological and cultural well-being. They do not aim to cure disease, nor hasten death. At the same time, they recognise that dying is a natural part of living.

Some areas have a hospice with an inpatient unit, which may have beds available for short-term stays. These can only cater for a very limited number of people at any one time. There is usually a strict criteria for admission, e.g. managing complex symptoms. Some hospices have a day stay unit as well. Most patients receive their hospice care in their own homes, including if patients reside in a residential care facility.

Hospices offer a team approach. Their services may include specialist medical care, nursing, social work, counselling/psychological support, spiritual care, occupational and physiotherapy, pharmacy, bereavement support and sometimes complementary therapies. This varies between hospices around Aotearoa, New Zealand. These services are free.

How can hospice/palliative care help you and your family/whānau?

Managing symptoms such as pain, nausea, shortness of breath and exhaustion

Hospice/palliative care services are the specialists in this area. They can usually guide you to get the most benefit from medicines and offer practical ways to manage your symptoms. Examples of this may include eating when you have no appetite, managing fatigue and/or coping with breathlessness. They can also guide you in likely changes ahead and help you and your family/whānau to prepare.

Emotional, psychological and spiritual support

Grief and loss experiences are different for everyone and can extend beyond grief over a palliative diagnosis. It is normal to feel a full range of emotions, including grief, loss, frustration and anger. It can be very helpful to have someone to talk things through with. Counselling and spiritual care services are available, free of charge, to both you and your family/whānau. This may help to identify coping strategies, a sense of purpose, hope, legacy, faith and meaning.

Support to stay at home, if you are able and wish to

Hospices have teams that call you or visit you at home or in your residential care facility. This can vary between hospices, but includes medical care, nursing, social work, counselling/psychological support, spiritual care, occupational and physiotherapy, pharmacy, bereavement support and sometimes complementary therapies. They can support you and your family/whānau to adapt to any changes and answer your questions. There is often access to after-hours support.

Complementary therapies

Most hospices provide a wide range of supportive activities such as social-education programmes, art therapy, massage, support groups, aromatherapy and/or meditation. You can ask your local hospice about what services are available.

Support to prepare for the end of life, if this is appropriate

This is useful at any stage of life. Hoping for the best and preparing for the worst will mean that you have your affairs in order. You may find looking at advanced care planning helpful. Refer to the link at the end of this document.

Other things to consider

Can you still receive active treatment, such as chemotherapy or radiotherapy?

- Yes, if this helps to keep you comfortable. However, the aim is to manage symptoms rather than cure the disease. Hospice teams work closely with treatment teams to provide the best care available.

Can you change your mind and opt out?

- Yes, at any time.

If you are at home, do you still see your own GP?

- Yes. Your GP is still the key person in your health care team. The community palliative care team will work with your GP.

Will you still need to see your haematologist?

- This depends on where things are up to with your treatment. You may not need to see your haematologist again when the focus is less on specialist haematology care and more on your comfort and quality of life. Your haematologist is still available for back-up support to your health care team.

Does being referred to hospice mean that you are dying?

- Not necessarily, it means that the focus of your care is improving the quality of your life, rather than extending it.

Are hospices religious?

- No. They welcome everyone who fits their medical criteria. They aim to support you in whatever spiritual practice, faith or religion you may, or may not, have.

How do you access palliative care?

You ask for a referral to your local service. If you are in hospital, there may be a specialised hospital palliative care team. If you are at home, contact your local hospice or your GP. If you are in a residential care facility, talk to the manager or the local hospice.

Patients who are receiving support from hospice often wish they had been referred sooner. Don’t be afraid to initiate these conversations with your key health care professionals, or with your family/whānau. It can be very helpful to get to know your local hospice before you need it.

Each hospice service has its own guidelines. You will be assessed by someone from their service to make sure you meet their requirements.

What happens next?

You will connect with someone from the hospice or palliative care team, who will talk with you about how you are, how your symptoms affect you and what matters to you and your family/whānau. They will tell you what services are available locally. Together, you create a plan of care.

Are there alternatives to hospice?

Yes. There are times when hospice will not be available, perhaps because the hospice does not have capacity in their inpatient unit, you are outside of their geographical area or maybe you are too well. Hospices often have strict criteria, in this case you can approach your GP for advice.

In situations where you are not eligible to stay at your local hospice, or you are not wanting to go to hospice, you may consider staying at home or moving to a residential care facility.

Staying at home

Depending on your overall well-being, you may need extra help to stay at home while managing your condition. You can ask your GP for a referral for a needs assessment. You may be eligible for personal care, home help or respite care. Alternatively, you could pay for a private home-help service. If you need equipment, hospice or your treating hospital might be able to provide this.

Residential care facilities

The process for moving to a residential care facility requires a needs assessment. A hospital or hospice social worker can facilitate a referral for the assessment and give you an indication of costs and possible funding.

It is important to ask questions. Some ideas of things to consider and general guidance can be found in the links at the end of this document, or you can approach the hospital/hospice social worker or your GP for support.

If the decision is made to go into a residential care facility, such as a private hospital or rest home, there are many areas for consideration.

Here are some helpful questions you can ask:

- What can my family/whānau and I expect when I move into a residential care facility?
- How are decisions made about my care?
- How is the quality of your service monitored?
- To what degree does your service deliver palliative care?
- What's your relationship with the local hospice?
- How frequently are residents seen by a doctor? Is there a doctor available after hours?
- What is your staff to patient ratio?
- What level of training do your staff have?

- What additional costs can I expect?
- If there are concerns about care, how do these get resolved?

For a thorough and useful tool, we recommend downloading the Eldernet residential care checklist via the link below, or ask a social worker for a copy.

Where can I find more specific information on choosing a residential care facility or preparing for the end of life?

- Options for residential care: Information on residential care and a comprehensive checklist of things to consider. www.eldernet.co.nz/residential-care
- Long-term residential care for older people: Guidance for moving to residential care. www.health.govt.nz/our-work/life-stages/health-older-people/long-term-residential-care/residential-care-questions-and-answers
- Hospice NZ: https://www.hospice.org.nz
- Advance care plan: Guidance for thinking and talking about what is important to you at the end of your life. This can be done at any time, and recorded for future reference. www.hqsc.govt.nz/resources/resource-library/my-advance-care-plan-and-guide/
- Create my plan, Te Hokinga ā Wairua: A practical step-by-step list of things to consider and attend to. This includes legal and financial matters as well as wishes for funeral services or tangi. https://endoflife.services.govt.nz/create-my-plan
- Health and Disability Commissioner: If you have any concerns about the level of care, contact your advocate for advice and support. www.hdc.org.nz

Thinking about the end of your life and wondering how this will be is a natural part of living. You can talk to your family/whānau, GP or a hospice professional. Your LBC Support Services Coordinator is also available to you to talk through any concerns.

QUESTIONS & NOTES

Important information available online

For more information and to download other fact sheets, see our website **www.leukaemia.org.nz**

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If you would like to get in touch:
Call: 0800 15 10 15
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Or visit one of our Support Services offices in Auckland, Hamilton, Wellington, Christchurch or Dunedin