Palliative care aims to help people with life-threatening illness and their family to live as well as possible within the limitations of their illness. It focuses on improving the quality of a person’s life by helping them to manage any physical, emotional, social, cultural or spiritual problems they may have as a result of their illness or its treatment. Practical and emotional support is also provided for families and carers. A particular focus is on managing pain, nausea and other troubling symptoms.

Although palliative care is often provided at the end of a person’s life, it is not only for people who are dying. It can be provided and is beneficial at any time for a person with serious illness, even while they are getting other treatments. Palliative care can also be given at the same time as other treatments like chemotherapy, antibiotics, and surgery.

Who provides palliative care?
It can be provided by a haematologist and the wider health care team or a General Practitioner (GP). Often haematologists or GPs will seek the advice and support of a specialist palliative care service depending on a person’s needs and their family’s resources.

Specialist palliative care services are made up of a team of health care professionals who are very experienced in treating people with serious illness. The team includes doctors, nurses, allied health professionals (physiotherapists, occupational therapists, dieticians), social workers, counsellors or psychologists, pastoral care workers, and volunteers.

Where can care be provided?
Where a person receives palliative care is dependent on their needs, their preference, how well they can function physically and how much support is available.

Specialist palliative care services can be provided in many places including the home, hospital, out-patient department, palliative care unit or hospice, or an aged care facility. A specialist palliative care service can support people who wish to be at home when they die rather than in hospital.

While supports can be put in place to help this to happen, where a person receives care at the end of their life is often dependent on their specific needs and how much help family and carers can provide.

A specialist palliative care service will help guide patients and their families to make decisions about the best place care can be provided.

When is palliative care best provided?
Since palliative care is focused on managing troubling symptoms and promoting quality of life, it can be introduced at any time depending on the needs of the patient and their family. People with haematological cancers often experience fluctuating levels of health and can get sick very quickly; so in some situations it may be recommended that palliative care is introduced early.

What is Advance Care Planning?
A key goal of palliative care is to help patients and their family to understand and actively participate in decisions about their healthcare.

Advance Care Planning is an important process where patients and those close to them can have open discussions with their health care team about their illness and the potential for them to become very unwell. Patients can talk about their wishes for future care in case they become too unwell to make decisions or speak for themselves.

Patients may also choose to make a legal record of their wishes using an Advanced Health Care Directive form or Statement of Choices Form.

Another important part of Advance Care Planning is giving someone you trust the legal right to make decisions about your health care if you are unable to do so. This is called appointing an Enduring Power of Attorney. It is important for all people to engage in Advance Care Planning, but more so if they have a serious illness such as cancer.

If a person with a haematological cancer has any of these documents, it is important their haematologist is aware of them.
Why should people do Advance Care Planning?
For people with serious illnesses, having open conversations with family members and health care professionals about the way they wish to live and be cared for is important.

These conversations help health professionals and families understand a person’s goals and preferences and what an acceptable quality of life is to them.

This will allow health care professionals and families make better decisions for a person who is unable to make decisions for themselves.

Where can I get more information about palliative care and Advance Care Planning?
If you have any questions related to palliative care or want to know about the services that are available to you, talk to your haematologist or your GP.

They can refer you to or put you in contact with your nearest specialist palliative care service. You can also search the National Palliative Care Service Directory to find a service in your area (www.palliativecare.org.au). This website also has links to more information and resources regarding palliative care.

If you would like to complete an Advanced Health Care Directive, Statement of Choices form, or nominate an Enduring Power of Attorney, speak with your GP or haematologist. You can also find more information at the following website: www.publicguardian.qld.gov.au/adult-guardian/health-care-decisions/advance-health-directive.

The Leukaemia Foundation of Queensland’s Support Services team is also available to discuss any concerns you may have. Contact us on 1800 620 420, or email qldsupport@leukaemia.org.au.

The Leukaemia Foundation of Queensland would like to thank the following people for their help in compiling this factsheet:

Elise Button – PhD Candidate, Queensland University of Technology; A/Nurse Researcher, Cancer Care Services, Royal Brisbane & Women’s Hospital

Allison Lovell – Clinical Nurse Consultant, Palliative Care Service, Royal Brisbane & Women’s Hospital

COMMON MISUNDERSTANDINGS ABOUT PALLIATIVE CARE

» Palliative care is not end of life care. Palliative care is often provided at the end of life but it can also be provided at any time for a person with a life-threatening illness.

» Being referred to a specialist palliative care service does not mean that the doctors think a person will die soon. Many people are referred when they have troubling symptoms or when they are first diagnosed with a life-limiting illness. Being referred early enables a specialist palliative care team to support a person easily throughout their illness depending on their needs.

» Palliative care is not about stopping all treatment. People who receive palliative care also continue to receive other medical treatments such as chemotherapy, antibiotics, investigations and surgery. The care provided to a person is suited to their needs and wishes, and the particular circumstances of their illness.

» Receiving palliative care treatments and taking strong pain relief medications such as morphine does not speed up a person’s death. Palliative care treatments are given to relieve suffering and are managed carefully by the health care team.

» Palliative care is actually not about dying; rather it is about living as well as possible with a serious illness. The word palliative means to reduce the severity or intensity of an illness.