

Palliative Care Information Kit for Cancer Patients & their Families

Holistic Approach & Strive for Quality of Life

Organisers



Introduction

Light in the Darkness

— Information and Resources for Palliative Care Cancer Patients and their Families with Chinese Background

Many Chinese people associate palliative care with end-of-life care due to the fear and taboo connected to the subject of death. Majority of the patients and their family members avoid discussing the need for palliative care services as many of them do not know how palliative care can help them with better quality of life during their cancer journey.

This project involves the development of a culturally and linguistically appropriate Chinese information kit that will help the Chinese community to better understand the concept and scope of palliative care services and provide guidance on how to access appropriate services.

CanRevive conducts this project in partnership with the Australian Chinese Medical Association (ACMA) and Calvary Health Care Kogarah, is funded by Cancer Institute NSW under the 2017-2018 Innovations in Cancer Control Grant. We would like to thank the many members of the Chinese community who contributed to the development of this resources by sharing their experiences, views and opinions.



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What is Palliative Care?

Palliative Care is translated into different Chinese terms in different regions. According to the World Health organization (WHO), the definition of palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems



Myths about Palliative Care

Palliative Care ≠ End-of-Life Care

Palliative Care does not mean End-of-Life service or End-of-Life care straight away. Some symptoms encountered by patients during treatment can be relieved through palliative care such as managing breathlessness, nausea or pain. When symptoms are under control and patient's condition is improving, the patient can stop palliative service and return to normal treatment. Therefore, palliative care can be temporary; it does not mean that the patient has reached the final stage of their life.

Admission into palliative care hospital ≠ Way of no return/deathbed

Admission into a palliative care hospital does not necessarily mean that patients have embarked on path of no return, or that their days are numbered. Palliative Care respects life and regards death as a natural process. It focuses on improving the quality of life of the patient and relieving symptoms. Once the condition is stabilized, the patient can go home or resume normal treatment.

Palliative Care ≠ Opioid Injection

Palliative Care is much more than injecting opioids for patients. In fact, not all patients suffering from terminal cancer will experience pain. In addition to pain relief measures such as morphine or other opiate pain killers, Palliative Care also employs a range of other care measures, such as anti-shortness of breath and measures designed to reduce anxiety and fear, to make patients and their families feel better emotionally, physically, socially and spiritually.



Morphine injection ≠ Premature Death

Can morphine injection lead to premature death? Morphine can effectively relieve pain and shortness of breath and will not readily become a dependency if administered under doctor's supervision. At times doctors increase the dosage as the condition deteriorates and the pain becomes more acute. The purpose of morphine is pain relief, not euthanasia. Correct use of morphine will not lead to premature death. As doctors point out: 'patients pass away because of their illness, not morphine; patients will still pass away even if morphine is not used.' If shortness of breath and pain aggravate the painful process of dying, it is appropriate to use medication to relieve this pain.

Palliative Care ≠ Euthanasia

Palliative Care is not euthanasia, which is injecting lethal drugs or taking certain measures as a way to end the life of a patient with an incurable disease who is suffering from pain. Palliative Care is not about ending a patient's life. Care workers won't do anything that is illegal under current law and regulations.

Consent to Palliative Care ≠ Doctor gives up on the Patient

When a doctor sees patients suffering from various discomforts such as vomiting, constipation or pain, as a reaction to or result of the treatment, the doctor might make a referral to a palliative care specialist to relieve the symptoms for the patients. Palliative Care does not disrupt normal course of treatment; patients can receive treatment and palliative care at the same time. Therefore, receiving palliative care does not mean that doctor has given up on the patient. The medical team will continue to focus on patients, maintain their quality of life and provide care for the whole person. Even if further treatment is not considered by the doctor, patients can still consider complementary or traditional therapies such as Chinese medicine and acupuncture.

Take no Action to save the Patient ≠ Being Inhumane/Unfilial

Many believe that taking no action to save patients is inhumane; and from the perspective of their children, it is unfilial. For irreversible medical conditions, some life sustaining treatments may temporarily prolong life, but they probably do not mean much for patients except for postponing the arrival of an ending, and to a large extent, aggravating physical pain (for example, intravenous nutrition liquid may spur the growth of cancer cells, resulting in internal bleeding and organ failures; CPR may result in broken ribs) and mental stress. Is this humane to patients? If their wish is to not to go through any meaningless rescue, then respecting their wishes should be considered as a filial act of the children.

Receiving Palliative Care ≠ Life will be Shortened

Receiving Palliative Care does not mean that a patient's life will be shortened. The main focus of Palliative Care is improving quality of life and relieving physical discomfort or pain, which may contribute to a longer life than predicted.

Doctor stops the feed for patients ≠ Let patients starve to death

Does the doctor stop the feed for patients to let them starve to death? No! Ms. Cicely Saunders, Palliative Care initiator, said that 'we'll do whatever we can to help the patients to enjoy their last moment in life and die in peace'. The focus of Palliative Care is to let patients maintain their dignity and quality of life at the last stage of their lives. For patients who are dying and whose organs have stopped functioning, feeding food and fluid would only increase the burden on the body and cause more pain. Instead of providing futile life sustaining treatment, the doctor would suggest stopping any feed for the patients and letting the patients pass away in peace, not intentionally making the patients starve to death.

Stop further treatment ≠ Death within days

The reason for stopping further treatment is because further treatment would cause more harm to the patient, or the treatment itself is found futile. Research shows that improving the quality of life (such as pain management) will make patients feel better and even live longer.

Aims and benefits of Palliative Care

Palliative Care is an approach that improves the quality of life of patients with life-threatening illness. The care is provided by a medical team composed of medical professionals and support staff to minimize pain and address other physical, psychosocial and spiritual problems, so that patients are given sufficient attention to their symptoms and emotional comfort before their peaceful death.

The benefits of Palliative Care are threefold

Care for the whole person

Palliative Care focuses on patients, not their illnesses. It provides patients with a complete range of medical and nursing care necessary for dealing with their mental, physical, psychosocial and spiritual issues


Care for the whole family

Care is not only given to patients, but also to their families, for example, by facilitating the communication between patients and their families, assisting families to access social support and welfare benefits, etc

Care for the whole journey


Palliative Care provides care to terminally ill patients until their death and assists their families to go through the whole bereavement process





How to access Palliative Care service and get referred?

Patient and family can



contact the treating
doctor or oncologist
to make referrals

ask the GP for
information about
palliative care service. If
require, ask the GP to
make referrals

ask the
community nurse
to make referrals

Where can I receive Palliative Care? What are the services?

Palliative Care services from

- ◆ Acute Hospital
- ◆ Sub-acute Hospital
- ◆ Palliative Care Day Centre
- ◆ Palliative Care Hospital (Hospice)
- ◆ Residential Aged Care Facility
- ◆ Home Based
- ◆ Palliative Care Day Clinic

Palliative Care hospital services include

- ◆ Inpatient and Outpatient
- ◆ Home Visits
- ◆ 24 hour Phone Support
- ◆ Palliative Care Gymnasium
- ◆ Symptom Management, such as pain, nausea, vomiting or breathlessness
- ◆ Emotional Support to patients and their families and cater for their psychological and spiritual needs
- ◆ Other support services, such as financial support, home care, community transport
- ◆ Respite Referrals for patients and their families
- ◆ Medical Equipment Loans, such as wheelchair, medical bed
- ◆ End-of-Life Care
- ◆ Counselling & Bereavement Support

Members of a Palliative Care team

The care is provided by a team composed of medical professionals and support staff for the purpose of improving the quality of life of the patients and their families.

Members of the medical team include

General Practitioner (GP)	This is the first point of contact when a cancer diagnosis is given. When patients are placed under palliative care, GP who is experienced in palliative medicine will consider all the physical, psychosocial and spiritual issues that the patients and their families are facing with, answer questions and make referrals
Oncologist	This is the treating doctor for patients. When necessary, a referral can be made to palliative medicine physician for relieving various symptoms and pain
Palliative Medicine Physician	Provide pain and symptoms management assessment and advice, including Ambulance Care Plan
Palliative Care Nurse	Facility or community based palliative care nurse works with palliative medicine physician or GP and provides appropriate nursing support to manage the pain and symptoms
Occupational Therapist	Provide assessment of patient's home environment and equipment, organize modifications and provide education sessions, support patient's needs when receiving palliative care at home
Physiotherapist	Provide guidance on movement and functional exercises
Dietitian	Provide guidance on diet and nutrition
Social Worker	Provide guidance and information about welfare benefits and make referrals to address financial and mental issues
Pastoral Care	Provide emotional and mental support to patients and their families and look after their religious or spiritual needs
Cancer Support Organisation / Volunteer	Some cancer support services such as CanRevive Inc will provide information and emotional support service to patients and their families, such as telephone support, home visit and hospital visit, etc

What to consider during Palliative Care?

Should patients receive palliative care in hospital or at home?

- It depends on patients' home conditions, including availability of suitable carers for routine caring tasks, suitability and sufficiency of home equipment and facilities. At the hospital patients are looked after around the clock, so that carers can have a break.
- If patients wish to receive care at home, some areas may need modification to ensure the safety of the patients and reduce the worry of their families. An occupational therapist from the palliative care team will pay a home visit to conduct an assessment and provide advice.

What is Advance Care Directive? What are the benefits of an Advance Care Directive for patients and their families?

- Many believe that 'quality of life is more important than length of life'. It is recommended that terminally ill patients should discuss with their families about an Advance Care Directive, which can specify whether they are willing to receive any treatment to prolong their life, including life-sustaining treatment such as CPR, assisted respiration or insertion of nasogastric tube, when patients reach a point of no return and show no response to any treatment. In other words, when patients are conscious, they make their own decision as whether to accept or decline any intensive care or use of life sustaining equipment when they become unconscious.

Benefits of Advance Care Directive:

- It reflects patients' own value in life – it provides terminally ill patients an opportunity to make their own decision on basis of personal value as regards to what to do in the future, such as declining any physical and emotional pain associated with excessive treatment / ineffective life-sustaining treatment.
- It avoids future disputes – consider your families you love, avoid any potential arguments and conflicts that might arise when they have a tough decision to make, so patients can enjoy a peaceful departure from this world.
- Regarding the form, you can make enquiries with your GP, hospital social worker or palliative care team and obtain help to fill out the form.
- There are 5 sections in the form (from NSW Health):

(i) Patient's personal details & enduring guardian

(ii) Personal values about dying

(iii) Directions about medical care

(iv) Specific requests for organ & tissue donation

(v) Authorization and witness signature

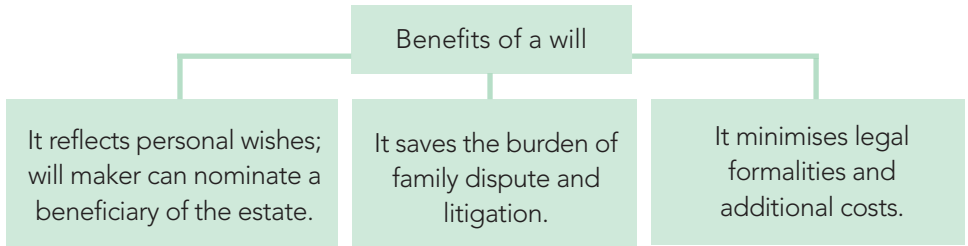


For more information about Advance Care Directive, visit www.advancecareplanning.org.au or call National Advisory Helpline: 1300 208 582.

Form for Advance Care Directive can be downloaded from NSW Health website: <http://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf>

What can patients do for their families? Will patients consider making a will?

A will is a legal document specifying how to distribute the estate. In absence of a will, your estate will be distributed in accordance with government regulations, in a way that might be contrary to your personal will to have it distributed to certain individuals or groups, and it may take a long time to finalize the distribution.



There are several ways to make a will:

- Private lawyer or you can contact The Law Society of NSW Solicitor Referral Service on (02) 9926 0300 or visit: www.lawsociety.com.au
- Contact Community Legal Centres NSW on (02) 9212 7333 or visit www.clcnsw.org.au for free legal advice.
- Contact NSW Trustee & Guardian on 1300 364 103 or visit www.tag.nsw.gov.au
- Purchase a Legal Will Pack from post office, newsagency or online and do it yourself. Seek help from professionals when necessary.

What is Power of Attorney?

When is it necessary to sign a Power of Attorney?

- Power of Attorney is a written document where the principal appoints and authorizes someone as a representative to act on his behalf and in his interest. It can be a legal document issued by one party; it can also be part of other legal documents (such as deed or agreement).
- If patients are still alive, but lack mental and physical capacity to deal with personal matters or finance or to make decisions, then a Power of Attorney is necessary for trusted families/friends to act on patients' behalf.

There are two types of Power of Attorney

General Power of Attorney

suitable for a specified period of time (such as overseas travel or admission to hospital) when you need someone to deal with financial matters (including managing bank accounts, paying bills, buying/selling shares or properties) on your behalf during this period. This authorisation ceases when you lose the capacity to make decisions

Enduring Power of Attorney

you authorise someone to make decision for you and deal with any financial matters for you when you lose the capacity to make decisions

- For terminally ill patients, an Enduring Power of Attorney is preferred when you are still conscious.

What can patients do if there are no families around?

- Patients can appoint a trusted person as Guardian to make decisions about their lifestyle (such as accommodation, medical treatments and services) when they lose the capacity to make decisions. Patients can specify the guardian's authority and roles in an Enduring Guardianship Form.
- You can contact a lawyer for help with the above-said documents or contact NSW Trustee & Guardian on 1300 364 103.

Frequently asked questions

If my English is limited, how can I communicate with medical staff?

- You can ask medical staff to contact Translating & Interpreting Service (TIS) on 131 450 for telephone interpreting service;
- Keep in touch with your GP, who can help with many questions;
- Request the hospital to arrange an interpreter before the next appointment;
- TIS telephone interpreting service is free for contacting government departments and public hospitals. Call 131 450 and say 'Cantonese' or 'Mandarin', someone will arrange an interpreter for you on line; once the interpreter is connected, ask them to put the call through to the department or the number you want to contact.

Can I seek second opinion from another doctor in regards to the need or referral for palliative care?

You can seek second opinion from another oncologist or palliative care specialist.

Is there a charge for palliative care service?

Palliative care at home or in hospital arranged through public system is free for Medicare card holders. There may be a fee for some medications or equipment. Please consult relevant service providers for details.

How long will patients stay in a palliative care hospital?

Patients are admitted to a palliative care hospital for many reasons, commonly for relief of symptoms and pain management that have become impossible to achieve at home. Another common reason is that patients have reached the End-of-Life stage, so hospital is a preferred place for palliative care. Average hospital stay is 14 days.

Can patients go home for a break from the palliative care in hospital?

If the palliative care physician believes that symptoms are under control or show improvement and patients and their families agree, patients can go home for a break. They can also return back to their families on weekends and public holidays during their admission to hospital.

Are there any restrictions on visiting hours in a palliative care hospital?

Families' company and friends' support are very important to patients, so general palliative care hospitals have no restrictions on visiting hours.

Can families stay overnight?

Families can stay overnight if patients live in a single unit or special suite in the hospital.

Does the hospital provide Chinese meals?

No, but families can bring their own food and heat it up at the hospital.

Can patients bring personal items, such as pillow and blanket, to the hospital?

Yes, any items that are important to patients, including family photos.

Can patients use palliative care service in another region?

Not recommended, as patients may lose home-based support from their local team.

Where to get support if patients are already experiencing financial difficulties or in financial hardship after they are diagnosed with cancer?

- Make an appointment to see the Medical Social Worker in the hospital for help and referral to relevant organisations;
- Apply to Centrelink for sickness allowance, disability pension or carer's allowance;
- Enquire about the one-off subsidy and interest-free loan from Cancer Council NSW.

What support is available to carers?

More often than not, carers for terminal cancer patients may feel mentally and physically exhausted, therefore they need support as well.

- For practical assistance such as transport, meals and housework, contact social worker in the hospital for information and referral about home and community support service;
- For mental health, contact social worker in the hospital, professional counsellors or health professionals;
- For emotional/information support, contact cancer support services such as CanRevive Inc.
- For respite service, contact Carer Respite Service.

(See "More Information and Support" on the next page for contact details of service providers.)

More information and support



Palliative Care/Cancer Information and Support

Organisation	Telephone	Website
Palliative Care Australia National organisation for palliative care	(02) 6232 0700	www.palliativecare.org.au
Cancer Council NSW Leading cancer support organisation in NSW. Provide information and resources in multiple languages to support those who are affected by cancer	Help Line: 131 120	www.cancerCouncil.com.au
NSW Palliative Care (after hours) Helpline A specialist palliative care nurse to answer your enquires	1800 548 225	
CanRevive Inc. The first Chinese cancer support organisation in NSW	(02) 9212 7789	www.canrevive.com

Benefits / pensions

Organisation	Telephone	Website
<p>Centrelink Part of Department of Human Services. Responsible for implementing Australian welfare scheme</p>	<p>131 202 (Multilingual Line) Say 'Cantonese' or 'Mandarin'</p>	<p>www.humanservices.gov.au</p>

Translating and Interpreting

Organisation	Telephone
<p>TIS (Translating & Interpreting Service) Provide interpreting service to any individuals or agencies in Australia to enable non-English speakers to access service and information over the phone</p>	<p>131 450 (24 hours) Say 'Cantonese' or 'Mandarin'</p>

Legal Advice

Organisation	Telephone	Website
<p>LawAccess NSW Provide legal information/advice over the phone and referral to Legal Aid and Community Legal Centre near you</p>	<p>1300 888 529</p>	<p>www.lawaccess.nsw.gov.au</p>
<p>Legal Aid NSW Assist with legal aid funding application and relevant services</p>	<p>(02) 9219 5000</p>	<p>www.legalaid.nsw.gov.au</p>

Practical Support

Organisation	Telephone	Website
<p>My Aged Care For people aged 65 or above. A starting point for obtaining various aged care services and information, such as eligibility for services, service categories and costs</p>	<p>1800 200 422</p>	<p>www.myagedcare.gov.au</p>

Practical Support

Organisation	Telephone
<p>Respite, home care and transport support: Commonwealth Respite and Carelink Centre</p> <p>National information centre for respite service and relevant support</p>	1800 052 222

Counselling

Organisation	Telephone	Website
<p>Cancer Council NSW</p> <p>Leading cancer support organisation in NSW</p>	<p>Help Line: 131 120</p>	www.cancercouncil.com.au
<p>Carers NSW</p> <p>Focus on improving the lives of carers</p>	1800 242 636	www.carersnsw.org.au

Others

Organisation	Telephone	Website
<p>Ambulance Care Plan (Authorised Adult Palliative Care Plan)</p>		www.slhd.nsw.gov.au/btf/pdfs/Amb/Adult_Palliative_Care_Plan.pdf
<p>Carer Gateway</p> <p>Website and phone service for carers. Provide information and support</p>	1800 422 737	www.carergateway.gov.au

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Disclaimer

While every effort has been made to ensure that the information in this kit is as up-to-date and accurate as possible, CanRevive Inc. does not guarantee the accuracy, reliability or currency of the information. CanRevive is not responsible for, and expressly disclaims all liability for, damages of any kind arising out of use, reference to, or reliance on any information contained in this directory. Please inform CanRevive Inc. if you notice any errors or inaccuracies in this publication.

About CanRevive Inc.

CanRevive Inc. is a public benevolent institution, established in 1995 at Haymarket, Sydney, by two cancer survivors and one carer to support Chinese speaking people through their cancer journey. Its aim is to help minimise the impact of cancer on patients and their families by providing information and emotional support to cater for their cultural and linguistic needs. An extensive range of support services is provided by trained volunteers and professional staff, such as support groups, phone support, home and hospital visits, public information sessions, complementary therapy programs and interest groups. Please visit our website www.canrevive.com for more information.

About Australian Chinese Medical Association (ACMA)

The Australian Chinese Medical Association Inc (ACMA) in NSW was formed in 1990 as being the only medical association formed by registered medical practitioners with Chinese background at that time. Back then, the Chinese community was at its nascent stages of development and it was felt that an organisation which promoted and responded to health issues affecting the Australian Chinese community was required. The Association also allowed members to stay connected at professional and social levels. With the expanding Chinese community and the increased integration of the Chinese into the broader community, the role of the ACMA has changed gradually throughout the years. The current aims of the ACMA centres around: professional networking, community health, including contribution to charitable causes and organisations, continuing medical education and social exchange. Furthermore, ACMA has also established ACMA Charitable Trust. It was established in 1992 as a registered public charity in the state of NSW. The Trust ongoingly donate fund to support education and research in medicine, relief of distress and hardship of people in need, provide scholarship and bursaries to promote the undertaking of medical research and studies, as well as to make donations to other publicly registered charities.

About Calvary Health Care Kogarah

Calvary Health Care Kogarah have been providing Palliative Care for over 50 years. Their goal of Palliative Care is to help the patient and their loved one achieve dignity, comfort and maximise the quality of life. They provide palliative care as an inpatient service, at home or in residential care facilities. The patient can be admitted for pain and symptom management, respite care or end of life care. Their Community Palliative Care Team provides palliative care to people in the St George District and the Sutherland Shire. Types of service can be delivered as home visits, in clinics and telephone advice for all who had been referred.

They use a team approach to address the needs of patients and their families. Their care is coordinated with other services and is focused on the whole person with aim to look after the patient's physical, emotional, social and spiritual needs.



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Information and Resources for Palliative Care Cancer Patients | Families