CANCER SHARED CARE

TOOLKIT FOR SHARED CARE PILOT

GANNAWARRA SHIRE - 2023

HELPING IMPROVE THE HEALTH AND WELLBEING OF PEOPLE ON THEIR CANCER JOURNEY

Patient name	
Date of birth	
Medical record number	

Murray PHN acknowledges its catchment crosses over many unceded First Nations Countries following the Dhelkunya Yaluk.

We pay our respects and give thanks to the Ancestors, Elders and Young People for their nurturing, protection and caregiving of these sacred lands and waterways, acknowledging their continuation of cultural, spiritual and educational practices.

We are grateful for the sharing of Country and the renewal that Country gives us. We acknowledge and express our sorrow that this sharing has come at a personal, spiritual and cultural cost to the wellbeing of First Nations Peoples.

We commit to addressing the injustices of colonisation across our catchment, and to listen to the wisdom of First Nations communities who hold the knowledge to enable healing.

We extend that respect to all Aboriginal and Torres Strait Islander Peoples.

ACKNOWLEDGEMENTS:

We would like to acknowledge that much of the source material for this toolkit was originally created based on consultation information obtained with cancer consumers, carers and health service providers between 2022-23 living and/or practising in the Gannawarra Shire, Victoria. Murray PHN would like to acknowledge and thank them for their contribution to this document.

The information in this document does not constitute medical advice and Murray PHN doesn’t accept any responsibility for the way this document is interpreted or used.

Funding for this document has been provided by the Victorian Government Department of Health as part of the Shared Cancer Care initiative.

While the Victorian Government Department of Health has contributed to the funding of this material, the information contained in it does not necessarily reflect the views of the Victorian Government and is not advice that is provided, or information that is endorsed, by the Victorian Government. The Victorian Government is not responsible in negligence or otherwise for any injury, loss or damage however arising from the use of or reliance on the information provided herein.

Contents

OVERVIEW

The Victorian Cancer Plan aims to identify and implement sustainable models of cancer shared care, building and developing on existing survivorship, and enabling the acute and primary workforce to deliver high-quality shared care for regional Victorians living with cancer.

As part of Murray PHN's Cancer Shared Care project, this toolkit has been created to help general practices undertake self-directed, stepped cancer shared management in the Gannawarra Shire. Content has been developed in consideration of information shared by cancer consumers, carers and practitioners in Gannawarra Shire on their experiences with cancer services from diagnosis and treatment to follow-up care.

A half-day consumer workshop in Kerang was held to begin the co-design process by exploring the needs and preferences of those with a lived experience of cancer. Two stakeholder workshops and a follow-up meeting with Northern District Community Health resulted in the first draft of a shared care model. This draft has been further refined with feedback from a regional services planner and oncologist from the Bendigo Cancer Centre.

MODEL OVERVIEW

The general practice will be the primary local hub in this model with a 'whole of general practice' approach that uses the GP, nurse practitioner, practice nurse and administration staff. Most consultations will be nurse-led and GP-supported. The shared care model in this pilot will occur with specialist services that share care with the local Gannawarra Shire Service Network. A range of local services will be mobilised to support patients, their carers and communities according to their needs and preferences. Overview on this model network is available below:

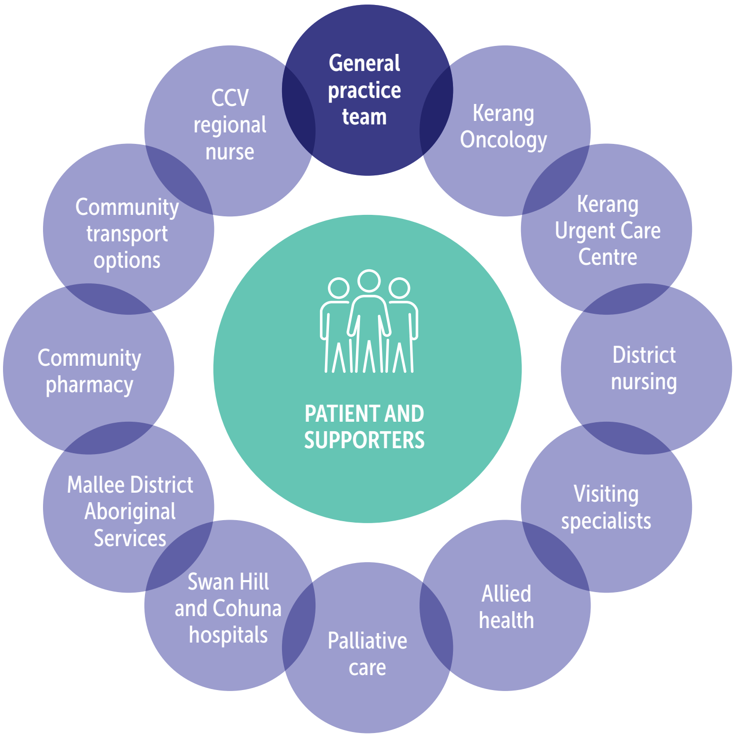


Figure 1. The Gannawarra Shire Cancer Shared Care (CSC) model – Gannawarra Services Network

The general practice team will actively liaise and collaborate with other providers in the Gannawarra Services Network. Patients and their carers will be equipped with information and guidance on how to navigate services and access support both within and outside of local services networks based on their needs. Specialists outside of this network will be informed of the proposed shared care model and encouraged to provide information and support to enable timely linkages with services and supports.

New services and programs will be added to the Gannawarra Shire Service Network as they are identified or are developed e.g. if a Wellness and Life After Cancer program is able to be offered locally.

Consultation with the general practice team implementing this model will occur throughout the pilot for feasibility assessment. This toolkit will offer providers a localised resource document where model pathways and complementary resources are located. Providers will be also engaged to upload checklists available in patients, medical records for future consultation and monitoring.

This toolkit is divided into three stages:

Stage 1 Patient onboarding

Stage 2 Shared care management

- Diagnosis and treatment planning
- Mid-treatment (ongoing appointments)

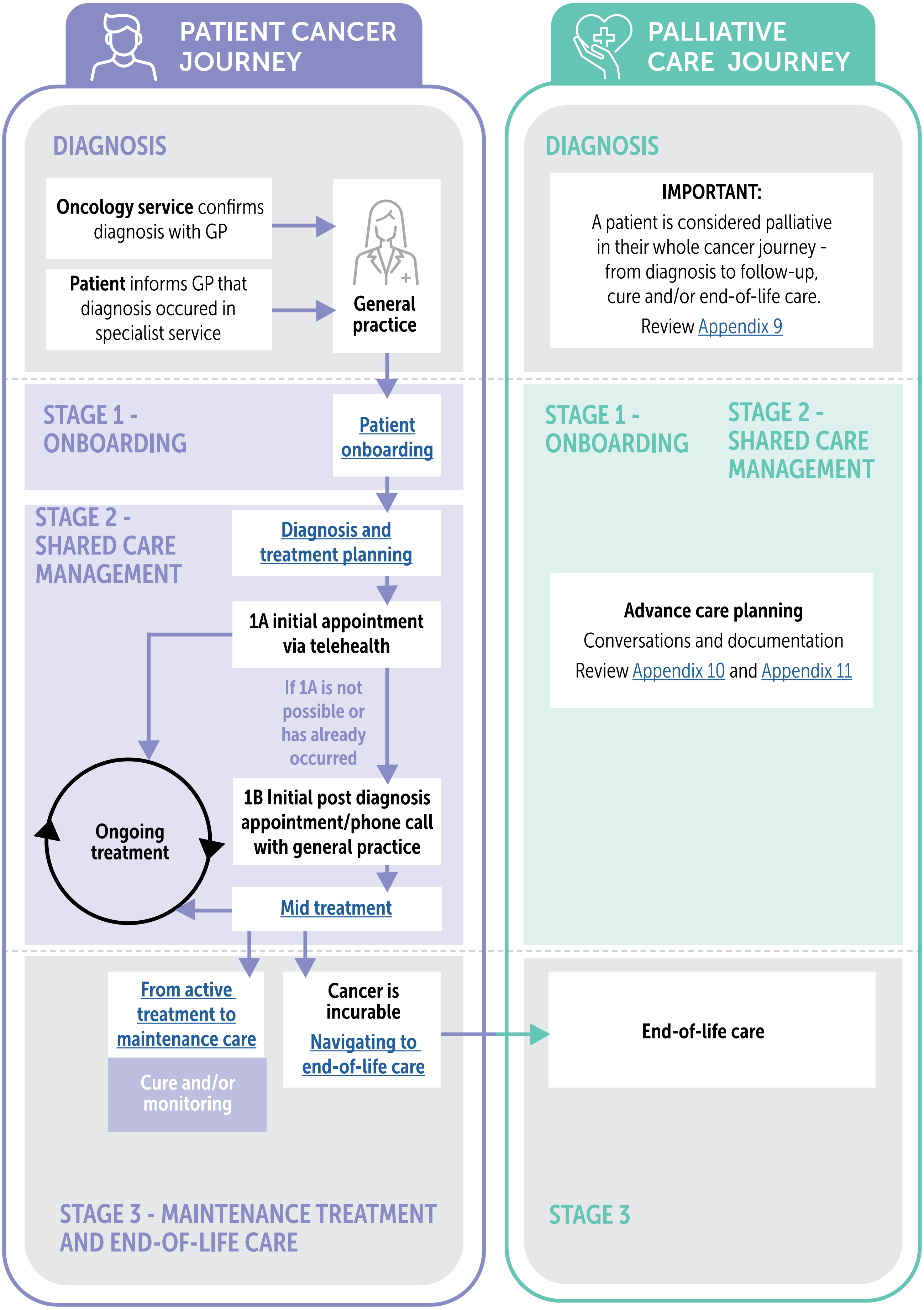
Stage 3 Maintenance treatment and end-of-life care

- End of active treatment/ transition to maintenance treatment
- When care is uncurable
- Navigating ongoing treatment/end-of-life care

HOW TO USE THIS DOCUMENT

This toolkit has been created as an interactive PDF to enable you to complete and use resources. You will ideally use Adobe Acrobat or a similar compatible program to fill out the forms. Providers are also invited to extract sections of this document and upload them in patients' medical records for future consultation and follow up.

FLOWCHART DEVELOPMENT



PATIENT CANCER JOURNEY

DIAGNOSIS

Oncology service confirms diagnosis with GP

Patient informs GP that diagnosis occured in specialist service

General practice

STAGE 1 - ONBOARDING

Patient onboarding

STAGE 2 - SHARED CARE MANAGEMENT

Diagnosis and treatment planning

1A initial appointment via telehealth

If 1A is not possible or has already occurred

1B Initial post diagnosis appointment/phone call with general practice

Mid treatment

Ongoing treatment

From active treatment to maintenance care

Cure and/or monitoring

Cancer is incurable

Navigating to end-of-life care

STAGE 3 - MAINTENANCE TREATMENT AND END-OF-LIFE CARE

PALLIATIVE CARE JOURNEY

DIAGNOSIS

IMPORTANT:

A patient is considered palliative in their whole cancer journey - from diagnosis to follow-up, cure and/or end-of-life care.

Review Appendix 9

STAGE 1 - ONBOARDING

STAGE 2 - SHARED CARE MANAGEMENT

Advance care planning

Conversations and documentation

Review Appendix 10 and Appendix 11

End-of-life care

STAGE 3

STAGE 1 - PATIENT ONBOARDING

Cancer shared care (CSC) patient onboarding checklist for general practice

This section provides a checklist of key actions after patients have been diagnosed with one of the following three tumour streams (colorectal cancer, lung cancer, breast cancer) and accepted to be included in this pilot.

The checklist offers providers a stepped approach to guide holistic assessment of patients' needs while offering system optimisation suggestions for comprehensive care coordination, timely referral and information handover between providers.

Disclaimer: It is important to notice that suggested responsible team members may differ across practices, governance and can be adapted to reflect organisation arrangements.

Task		Responsible
GP receives communication from oncology team or diagnoses patient with one of the cancer streams		
GP reviews and approves patient for admission to CSC pilot		GP
Verbal consent to participate in CSC pilot obtained and noted in patient file		Nurse/GP
Review supportive/survivorship care plan and/or oncology summary/report, if received		Nurse/GP
Add patient to Cancer Shared Care Participant data tracker		Admin
Identify patient CSC involvement in clinical software file and add relevant documentation and reminder alerts.		Admin
Initial appointment with GP (in-person)		
Consent and information	Provide patient with Appendix 1 - Cancer Shared Care (CSC) patient flyer and Appendix 2 - CSC Project Explanatory Statement and Consent Information	Nurse/GP
	Provide patient with any complementary information on their cancer type	Nurse/GP
	Record/check patient consent in medical notes	GP

Task		Responsible
Care planning and needs assessment	Complete GP and Patient Session Summary (Appendix 3), provide patient with a copy and add to patient file	Nurse/GP
	GP and patient discuss survivorship/supportive care plan and/or oncology summary/report, if received	Nurse/GP
	Identify referrals and supports required, using HealthPathways for referrals. Check Appendix 5	Nurse/GP
Multi-disciplinary team involvement	Identify patient's contact with other medical professionals and add to project Cancer Shared Care Participant data tracker	GP/Admin
	Review and list all medical and allied health professionals involved in patient's care and potentially to receive tests, report and patient care plans.	Admin
	Check with patients and team for their names, locations and updated details ***Tip: Share list with patient and carer for consultation***	GP/Admin
Out of hours support for patient and carer	Discuss urgent/emergency patient action plan	GP/Admin
	Share after hours advice services and helplines available to patient and carers	GP/Admin
	Review Non-acute and Acute Oncology Referral Healthpathways pages	GP
Follow-up	Follow-up appointments frequency and costs discussed ***Tip: Discuss any potential out-of-pocket costs the patient will need to cover for appointments, follow-up and potential procedures. Review MBS billing list on Appendix 6***	Admin
	Book next follow-up appointments with GP and/or nurse	GP/Admin
	Book nurse appointment for completion of Supportive Care GP Management Plans (GPMP) – *more information in the next section*	GP/Admin/ Nurse
	Provide patient the Distress Thermometer for completion prior to nurse appointment. Assessment is available online here and also in Appendix 4	GP/Admin/ Nurse
After appointment	Download and set up GMPM templates in your practice medical records. Instructions available in Supportive Care GP Management Plans (GPMP) – Appendix 7	GP/Admin/ Nurse

Task		Responsible
Cancer supportive care GPMP appointment (in-person)		
Before appointment	Download and set up GMPM templates in your practice medical records. ***Tip: Instructions available in Supportive Care GP Management Plans (GPMP) – Appendix 7***	Nurse
	Review survivorship/supportive care plan and/or oncology summary/report and test results if received	GP
During appointment	Complete Supportive Care GPMP with patient, using HealthPathways for referrals (Appendix 5)	Nurse
	GP reviews completed Cancer Supportive Care GPMP	GP
	Discuss patient multidisciplinary support and other care plans required: • Team Care Arrangements • Mental Health Care Treatment Plan • Case conference • Allied health ***Tip: Revisit Chronic Disease Management MBS item Appendix 6 for billing optimisation opportunities***	GP/Nurse
	Provide GPMP documentation and referral details to patient and carer	Admin
	Provide copies of documentation to oncology team	Admin
Follow-up	Cancer Supportive Care GPMP review appointment booked at three month intervals	Admin
Recurring GP appointments (in-person or via telehealth)		
Review Cancer Supportive Care GPMP		GP
Revisit urgent/emergency patient action plan		GP
Complete GP and Patient Session Summary. Provide patients with a copy and add to patient file		GP
Review appointments frequency and discuss costs ***Tip: Discuss any potential out-of-pocket costs that the patient will need to cover for appointments, follow-up and potential procedures. Review MBS billing list in Appendix 6***		GP/Admin
All medical professionals to receive test results, reports and patient care plans when updated ***Tip: Review list of providers and contact information with patient and carer***		GP/Admin/ Nurse
Move into Stage 2 – Shared care management		

STAGE 2 - SHARED CARE MANAGEMENT

Diagnosis and treatment planning

After completion of patient onboarding, active shared care management and treatment planning initiates. Care management and referral process checklists are provided below by stage of patient's treatment. This section is divided in two parts:

1. Diagnosis and treatment planning
2. Mid-treatment (ongoing appointment).

A suggested treatment planning protocol is also provided when initial diagnosis has not taken place in general practices. It also reinforces telemedicine resource opportunities for timely access to care for patients living in regional and remote areas.

1A INITIAL PATIENT APPOINTMENT VIA TELEHEALTH

Note: if 1A is not possible or has already occurred go to 1B

Initial patient appointment	
Involved: patient, family member/support person, oncologist, GP/practice nurse	
Telehealth	
Initiated by health professional who recruits patient to the CSC. ***Tip: Case conferencing MBS item numbers are available to perform these discussions (items 735, 739, 743).*** *For requirements, please review CDM MBS billing list in Appendix 6*	
Appointment checklist	
Before appointment	Review: Appendix 11 - Important conversations and advance care planning Appendix 10 - Early identification of patients requiring palliative care
During appointment	Checking in Advice for coping Assessment, treatment plan, goals of care. Check Appendix 8 for cancer shared education and training opportunities Addressing questions and concerns about treatment, side effects, tests, results, access to urgent care - Symptom and Urgent Review Clinic (SURC) - costs/other barriers to accessing care. Check Non-acute and Acute Oncology Referral Healthpathways pages Management of co-morbidities

Initial patient appointment	
Appointment checklist (cont)	
Follow-up	Referrals e.g. geriatric assessment, allied health, palliative care ***Suggestion: Review HealthPathways (Appendix 5)*** Next steps and what to expect ***Suggestion: Review Cancer Supportive Care HealthPathways.*** Review this pilot process, patient understanding and provide information Making future appointments as per the protocol (see next phase) ***Suggestion: discuss any potential out-of-pocket costs patient will need to cover for appointments, follow up and potential procedures. Review MBS billing list on Appendix 6***

1B. INITIAL POST DIAGNOSIS APPOINTMENT WITH GENERAL PRACTICE

Initial post-diagnosis appointment
Involved: patient, family member/support person, GP/practice nurse
In-person or via telehealth appointment: 1 - 5 days after diagnosis
Introduce role as part of the General Practice team Questions and concerns How are they coping Introduce local support services and Cancer Council Victoria services. ***Suggestion: Review*** Cancer Supportive Care HealthPathways. Access to urgent care process and key symptoms (SURC) Check Non-acute and Acute Oncology Referral Healthpathways pages
Move to Mid-treatment section when applicable

Mid-treatment (ongoing treatment)

GENERAL PRACTICE

In-person or via telehealth appointment
(rotate between both depending on care need complexity)

Providers: GP, practice nurse or nurse practitioner

Monthly to quarterly

Make a recurring routine appointment in advance throughout the expected duration of treatment. These will be alternating appointments with the GP and practice nurse or nurse practitioner

Offer support and services in those appointments based on where the patient (and carer) are at.

Appointment checklist	
Checking in	Review GP and Patient Session Summary (Appendix 3). GPMP and outcome of referrals Addressing questions and concerns about treatment, side effects, tests, results and rapid re-entry Review access to urgent care (symptom and urgent review clinic or other) **Check** Non-acute and Acute Oncology Referral Healthpathways Review costs or other challenges or barriers to receiving optimal care
Other demands	Management of co-morbidities and preventable health Revisit local support services and referral to Cancer Council Victoria referral services ***Suggestion: Review*** Cancer Supportive Care HealthPathways
Advance Care Directive arrangements	Guidance for formalising wishes: treatment goals, advance care plan, wills, powers of attorney - what to consider, rights and choices **Review** Appendix 11 - Important conversation and advance care planning Appendix 10 - Early identification of patients requiring palliative care Advance Care Planning HealthPathways page Provide patient with a copy of advance care planning factsheet.
Next steps	Advice for coping, navigating the system, recordkeeping (diary management) and self-management **Review** recording progress on My Cancer Care Record Folder Making/renewing specialist referrals and scripts Make ongoing/end of treatment appointment

Move to Stage 3 – Maintenance treatment and end-of life-care when applicable

STAGE 3 - MAINTENANCE TREATMENT AND END-OF-LIFE CARE

Transitioning from active treatment to maintenance care

From active treatment, the patient journey will progress into transitioning to follow-up or end-of-life management when a condition is incurable. The protocol below provides practitioners an opportunity to systematically enhance holistic monitoring, assessment and response to patients' needs in either of the outcomes of their conditions.

GENERAL PRACTICE

At the end of treatment plan	
In-person appointment with specialist via telehealth	
Providers: GP, specialist and patient/carer	
Schedule a telehealth end of treatment review and follow-up care planning discussion (patient and carer with GP in general practice, linking to specialist via telehealth).	
Appointment checklist	
Checking in	Targeted **Review** of GP and Patient Session Summary where specialist can contribute (Appendix 3)
Final treatment discussions	Addressing questions and concerns about treatment outcomes and completion Management of treatment and late cancer-related side effects to be aware of Methods to re-access specialist care if needed ***Suggestion: Review HealthPathways (Appendix 5)*** Reinforce local services, Cancer Council Victoria and other available services for additional support and guidance as needed. Ensure patient is informed and understand all information provided
Follow-up	Confirm follow-up frequency of appointments and testing required Complete CSC project client survey
If condition is uncurable, move to next section of this protocol	

When cancer is incurable – navigating ongoing treatment for end-of-life care

GENERAL PRACTICE

In-person appointment (avoid telehealth consultation whenever possible)

Providers: GP, practice nurse, nurse practitioner and specialist team if required via telehealth

Before considering patient for end-of-life management:

Read Understanding palliative care (Appendix 9)

Revisit Early identification of patients requiring palliative care (Appendix 10)

Contact a palliative care advice service for guidance and support: Palliative Care Advice Services or Loddon Mallee Specialist Palliative Care Consortium

Pre-appointment

Book an initial or extra long appointment with patient (in addition to other existing appointments)
TIP: MBS billing optimisation opportunities are available for palliative care conversations. Check Appendix 6

Ask patient to bring the carer/family member who has an active role in their disease journey

Appointment checklist

Checking in	Review GP and Patient Session Summary (Appendix 3) Addressing questions and concerns about tests, results and symptoms Follow-up examinations and tests if required (including reminder systems for tests as required) Symptom management
Palliative care needs management (introduction)	Discuss the end-of-life prognosis and what to expect ***Tip: Palliative care advice is available for difficult conversations. Contact Palliative care advice services or*** Loddon Mallee Specialist Palliative Care Consortium Supportive quality of life symptom management De-prescribing of unnecessary medications Discuss early referral to palliative care **Review** Palliative Care Healthpathways appendix section (Appendix 5) **In the instance the patient decides to stop with any active disease modifying treatment:** Contact a specialist service e.g. oncology, radiology Obtain advice from a palliative care specialist via Palliative care advice services or Loddon Mallee Specialist Palliative Care Consortium

Providers: GP, practice nurse, nurse practitioner and/or specialist team if required via telehealth	
Appointment checklist (cont)	
Advance Care Directive arrangements	Check status of advance care planning discussions and documentation Guidance for formalising wishes: treatment goals, advance care plan, wills, powers of attorney - what to consider, rights and choices **Review** Important conversations and advance care planning Appendix 11 and Advance Care Planning HealthPathway
Support services	Offer support and services in those appointments based on where the patient (and carer) is at, for: Discussing available range of supports: aids and equipment; pain management; optimising quality of life; forward planning and support for family **Review** Palliative Care Healthpathways appendix section (Appendix 5) Making/renewing other specialist/allied health referrals Discussing Team Care Arrangements and Mental Health Treatment Plans as options to access allied health and psychology services Offering counselling support for carers/family members Informing of available bereavement support services and how to access Revisit local support services and referral to Cancer Council Referral services **In the instance of patient dismissing palliative care referral:** Discuss with specialist team for advice and support. Contact Palliative Care Advice Services or Loddon Mallee Specialist Palliative Care Consortium ***Tip: Contact your local advice service for any further demands***
Next steps	If oncology treatment ceasing encourage appointment with oncology nurse Kerang District Health for final visit for support and linking to community services Book regular follow-up appointments until patient accesses palliative care specialist services **Offer a complementary appointment to the carer to assess their individual needs**
After appointment	Contact patient and carer in one week's time to check their wellbeing following their appointment

APPENDICES

APPENDIX 1

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CANCER SHARED CARE

What is the Cancer Shared Care project?

PATIENT INFORMATION

What is it?

Cancer shared care aims to improve your care following the end of your active cancer treatment.

It creates a direct line of communication between your GP and oncology team, to improve the care they can provide to you.

This will help you move from active treatment to focusing on your total health and wellbeing.

You will have a GP care plan, including priority appointments, to make sure all your needs are met.

What is needed from you?

- Attend GP appointments booked at your chosen time
- Complete a five minute survey online (in December)

What are the benefits?

- A health and wellbeing assessment to identify your care needs, including your medical, social and emotional health
- A care plan to support those needs, from medical, education, financial and household assistance, to spiritual or social support
- Your GP will work with you to plan regular appointments that suit you
- Referrals to other providers to meet all your care needs
- Direct communication between your GP and oncology team to support your care
- A rapid referral process if you need to see your oncologist outside your scheduled reviews.

For more information

Visit: murrayphn.org.au/cancersharedcare

HELPING IMPROVE THE HEALTH AND WELLBEING
OF PEOPLE ON THEIR CANCER JOURNEY

APPENDIX 2

EXPLANATORY STATEMENT AND CONSENT FOR PARTICIPANTS

CANCER SHARED CARE

INVESTIGATOR DETAILS

Principle investigator:	Vitor Rocha - Palliative Care Lead
Contact:	03 4408 5660 or vrocha@murrayphn.org.au
Organisation:	Murray PHN (Primary Health Network)

You are invited to take part in this pilot program for cancer shared care

Please read this Explanatory Statement before deciding to participate. If you would like more information about the study, please contact Vitor Rocha (contact details above).

What is Murray PHN?

Murray PHN is an independent not-for-profit organisation working to improve health and wellbeing of people across the Murray PHN region which spans from Mildura in the north-west, to Woodend in the south, across to Seymour and up to Albury, NSW

What is the Cancer Shared Care project?

The aim of the Cancer Shared Care project is to improve the health and outcomes of people living with cancer.

This project is testing a model of shared care. This is care that is shared between your oncology team, GP and other primary care providers, once your treatment phase is completed.

How can you contribute?

We invite eligible cancer patients to participate in the pilot to test the model.

If you agree to participate in the pilot, you will have follow-up appointments with both your oncology team and your general practice team.

These appointments are designed to assess and support your medical needs, as well as any other supportive care needs you may have for your general wellbeing and mental and emotional health. These supports could include education and information, practical assistance such as financial or household, and spiritual or social supports via community groups. Your needs will be assessed with your GP and oncology and practice nurses. Supports will then be put in place that best meet those needs.

Your oncology providers will send details about your cancer treatment to your general practice. Both providers will continue to share information to maximise the quality of your care and the outcomes for your health and wellbeing.

Consenting to participate in the project

Participating in this pilot is entirely voluntary and completion of the evaluation survey is anonymous. Any case study participation is also voluntary.

Once you have read this Explanatory Statement, please let your GP and oncology team know if you are willing to participate in the pilot. If you have questions or require more information, you can ask your GP or oncology team or contact Vitor Rocha, Murray PHN Palliative Care Lead (contact details above).

All responses are anonymous. Any information published will deidentified.

Confidentiality and storage of data

Your patient records as kept by your oncology and general practice providers are not part of this pilot and the confidentiality of these records is governed by your healthcare providers.

For the evaluation, survey data will be stored within Qualtrics survey platform – a secure system with access details known only to the researchers. All data, analysis and write-up will be kept on a password-protected computer. No hard copy data will be kept. The electronic data will be retained for five (5) years in secure storage. At this time, all results will be destroyed. Further information about the Murray PHN Privacy Statement, can be found on our website.

Results

Summary information from the survey and any case studies will be included in a report to be submitted to the Victorian Department of Health. Summary information may also be published by Murray PHN in our publications and social media.

Complaints

If you have any concerns or complaints about this project, please contact the Vitor Rocha, Murray PHN Palliative Care Lead (contact details above).

Recording consent

We invite eligible cancer patients to participate in the pilot to test a model of cancer shared care, designed to improve the health and outcomes of people living with cancer. The pilot supports the delivery of high-quality, safe and sustainable care that is shared between your oncology team, your GP and other primary care providers.

If you have read and understood this explanatory statement, please advise your oncology team or general practice team who have provided you with this statement if you are willing to participate in the pilot. You can provide your consent verbally. This consent acknowledges that:

- the research may not be of any direct benefit to me
- summary information gained during the study may be published, but my personal results will not be shared
- I am free to withdraw from the project at any time.

APPENDIX 3

CANCER SHARED CARE

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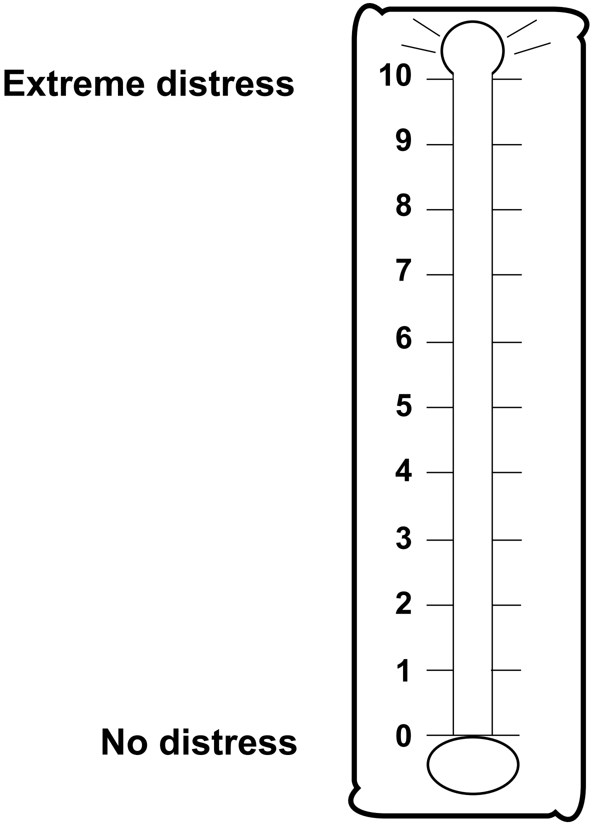
PATIENT SESSION SUMMARY

Name	
Date of birth	
Diagnosis	
Medical contact since last session:	
	Notes:
What we talked about today:	
	Notes:
Things you can try:	
Medication management	Reviewed ☐ Yes ☐ No
	Notes:
	Changes ☐ Yes ☐ No
	Notes:
Summary and plan	
Review date	
Provider name	
Provider signature	

NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.



PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns

- ☐ Pain
- ☐ Sleep
- ☐ Fatigue
- ☐ Tobacco use
- ☐ Substance use
- ☐ Memory or concentration
- ☐ Sexual health
- ☐ Changes in eating
- ☐ Loss or change of physical abilities

Emotional Concerns

- ☐ Worry or anxiety
- ☐ Sadness or depression
- ☐ Loss of interest or enjoyment
- ☐ Grief or loss
- ☐ Fear
- ☐ Loneliness
- ☐ Anger
- ☐ Changes in appearance
- ☐ Feelings of worthlessness or being a burden

Social Concerns

- ☐ Relationship with spouse or partner
- ☐ Relationship with children
- ☐ Relationship with family members
- ☐ Relationship with friends or coworkers
- ☐ Communication with health care team
- ☐ Ability to have children

Practical Concerns

- ☐ Taking care of myself
- ☐ Taking care of others
- ☐ Work
- ☐ School
- ☐ Housing
- ☐ Finances
- ☐ Insurance
- ☐ Transportation
- ☐ Child care
- ☐ Having enough food
- ☐ Access to medicine
- ☐ Treatment decisions

Spiritual or Religious Concerns

- ☐ Sense of meaning or purpose
- ☐ Changes in faith or beliefs
- ☐ Death, dying, or afterlife
- ☐ Conflict between beliefs and cancer treatments
- ☐ Relationship with the sacred
- ☐ Ritual or dietary needs

Other Concerns:

____

____

____

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

APPENDIX 5

RELEVANT HEALTHPATHWAYS

HealthPathways is an online resource that gives clinicians up-to-date, localised clinical and referral information. HealthPathways provides clear, concise guidance for assessing and managing patients with particular symptoms or conditions, as well as outlining the most appropriate referral pathways.

PATHWAYS		ABOUT THE PATHWAY
CANCER AND SUPPORTIVE CARE	Cancer supportive care	This pathway provides cancer-specific supportive care pathways and lifestyle recommendations.
	Breast cancer 1. Breast cancer – established 2. Breast cancer – follow-up 3. Breast cancer – screening	Provides disease-specific screening, management and follow-up, including referral pathways in accordance with disease trajectory. Important: also includes links to supplementary information resources for patients.
	Lung cancer 1. Lung cancer – suspected 2. Lung cancer – established 3. Suspected lung cancer assessment	
	Colorectal cancer 1. Colorectal symptoms – suspected colorectal cancer 2. Bowel cancer – screening and surveillance 3. National Bowel Cancer Screening Program (NBCSP) 4. Positive faecal occult blood test (iFOBT)	
	Adult survivors of cancer when a child or young	Lists specific recommendation and clinical assessment for survivors of cancer when a child or young adult.
	Other cancer streams	Lists a range of pathways of other cancer streams, including treatment and referrals.
CANCER EMERGENCY	Acute Oncology Referral (same day)	Provides region-specific information on acute and non-acute oncology referral pathways for timely care needs response.
	Non-acute Oncology Referral (> 24 hours)	
CARER OF THE PERSON LIVING WITH CANCER	Carer Stress and Wellbeing	Carers provide informal care and support to a family member or friend who has a disability, mental illness, or drug and alcohol dependency, chronic condition, terminal illness, or is frail. These pathways provide assessment and referral resources to consider carers needs and their wellbeing.
	Carer resources and support services	

RELEVANT HEALTHPATHWAYS

PALLIATIVE AND END-OF-LIFE CARE	Advance care planning	Provides information about the process of advance care planning, triggers for discussion, reflection resources and documentation. Legal forms for completion are linked to the HealthPathway.
	Palliative care overview	Overview of delivery of palliative care and the health professional's role.
	Palliative care referrals	Provides links for palliative care advice, as well as localised specialist palliative care services (SPCS).
	Voluntary assisted dying (VAD)	Provides a range of information, resources and guidance to assist in understanding or participating in voluntary assisted dying.
	Certification of death Victoria	The pathways listed guide the clinician in completing the documentation for certification of death in Victoria and NSW.
	Certification of death NSW	
	Bereavement	Provides clinical guidance and support for the patient after bereavement and loss.
	Guide to the palliative care MBS	A quick reference guide to Palliative Care Medicare Benefits Schedule (MBS).

Need access to HealthPathways?

You will need a username and password. Health professionals can request access online by clicking here.

APPENDIX 6

CANCER SHARED CARE

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CHRONIC DISEASE MANAGEMENT MBS ITEM NUMBERS MARCH 2023

COMMON CDM ITEM OVERVIEW

Item no	Service description	Claiming frequency	Details	Guide only - refer to MBS online
721	GP Management Plan (GPMP) ** 3 different formats available for differing clinical software*	1 per year	• No age restriction • Patients living in the community (not for RACF or hospital residents) • GPMP to be provided by patient's usual GP – Usual medical practitioner "have provided the majority of services to the patient in the past 12 months or will provide the majority of services in the following 12 months." *Must have a "chronic or terminal condition" - Present or will be for >6 months at GP discretion*	$150.10
723	Team care arrangement (TCA)	1 per year	• Same eligibility as GPMP+ • Complex care needs • Requires team care 3+ (specialist, allied health, other) *nurse depends if outside of their scope of general practice • All parties need to provide verbal/written confirmation of collaboration for ongoing management of patient prior to claiming	$118.95
732	Review of a GPMP/ TCA	3-6 monthly	• At 3, 6, 9 months • 12 months ACOC (for diabetes and asthma)	$74.95
729	Contribution to a care plan	3 monthly	• Alternate contribution to care plan e.g. acupuncture • Can be conducted by non-usual medical practitioner	$73.25
10997	Nurse service to patient with GPMP/ TCA	Max. 5 per calendar year – in addition to the usual care planning	• Follow up services for patients on a care plan • Checks on clinical progress; collect information to inform reviews • Review of medication compliance; provide self-management advice **Only chronic disease item number able to be co-claimed with GP consult* ** It would not be expected that item 10997 would be routinely claimed on the same day as item 721 or 723*	$12.50
10987	Nurse follow-up after health assessment 228 or 715	Max. 10 per year	• Available to Aboriginal and Torres Strait Islander people who have received a health assessment 228 or 715 • Examination and interventions as indicated by the health check	$25.35

CHRONIC DISEASE MANAGEMENT MBS ITEM NUMBERS

Item no	Service description	Claiming frequency	Details	Guide only - refer to MBS online
900	Domiciliary Medication Management Review (DMMR)	1 per year	• Complex medication requirement. • Conducted by registered pharmacists - reports back to usual GP	$161.10
903	Residential Medication Management Review (RMMR)	1 per year		$110.30
735 **739** **743**	Case conference - arrange	Max. 5 per year 15-20 mins, 20-40 mins, 40+ mins	• Arranged by general practice • GP, GP nurse e.g. nurse led clinic, allied health professional, cancer specialist, care coordinator	$73.55 $125.85 $209.80
747 **750** **758**	Case conference - participate	Max. 5 per year 15-20 mins, 20-40 mins, 40+ mins	• Participation by general practice • Lower to reflect administrative absence	$54.05 $92.60 $148.20*
10990 **10991*** *(rural/ remote)	Management of bulk-billed services	For those under the age of 16 or with a Commonwealth concession card		$7.65 *$ depends on MMR zone*

PALLIATIVE CARE ITEM OVERVIEW

Health Assessments (items 699, 701–707, 715)

A health assessment is the evaluation of a patient's health and wellbeing. Eligible practitioners use it to help decide if a patient needs:

- preventive healthcare
- education to improve their health and wellbeing.

Refer to MBS Online for more information on 75+ Health Assessments and Aboriginal and Torres Strait Islander Health Assessments.

Home Medication Reviews (item 900)

Domiciliary Medication Management Review (MBS Item 900), also known as Home Medicines Review (HMR), are comprehensive medication reviews completed by a credentialled pharmacist, on referral from a GP. These aim to maximise patient benefit from their medication regime and prevent medication related problems. A report is written by the pharmacist and forwarded to the referring doctor for their consideration of any issues raised.

Chronic Disease Management Plans (items 721, 723 and 732)

People with one or more chronic diseases require a range of interventions and supports over time. One approach to increase this support is to complete a GP Management Plan (GPMP) and/or Team Care Arrangement. Refer to MBS online for more information.

Practice nurse chronic disease (item 10987, 10997)

This item may be claimed by a medical practitioner where a monitoring and support service for a person with a chronic disease care plan (GPMP and/or TCA) is provided by a practice nurse or Aboriginal and Torres Strait Islander health practitioner, on behalf of that medical practitioner. This item can be claimed up to five times in a calendar year. Certain criteria must be met: search MBS Online.

Case Conferences (item 735, 739, 743, 747, 750, 758)

These services are for patients who have at least one medical condition that has been (or is likely to be) present for more than six months; or is terminal; and requires ongoing care from a team which includes a GP and at least two other members.

The team discusses a patient's history, identifies the patient's care needs, identifies outcomes to be achieved, identifies and allocates tasks to be undertaken, and assesses whether previously identified outcomes have been achieved.

There are different item numbers depending on the time taken, as well as if the GP is organising or coordinating (735, 739, 743) or just participating (747, 750, 758). Certain criteria must be met: search MBS Online.

Prolonged and Critical Condition Attendance (items 160-164)

These items are for consultations where a patient is in imminent danger of death. The time period relates to the total time spent with a single patient in 24 hours, even if the time spent by the practitioner is not continuous. Attendance may be claimed by one or more doctors. Certain criteria must be met: search MBS Online.

Helpful links

Chronic disease GP Management Plans and Team Care Arrangements

MBS Online

Murray HealthPathways: your pathway to better health outcomes

APPENDIX 7

SUPPORTIVE CARE GP MANAGEMENT PLAN (GPMP)

Care planning for patients living with cancer.

A GP Management Plan (GPMP) can be used to cover all considerations when creating a care plan for a patient living with cancer.

Medical record template download

The Cancer Supportive Care GPMP template is available for download. Simply select your medical software template version below:

- Best Practice
- Medical Director
- ZedMed

The template includes prompts to assist in the identification of cancer symptoms or cancer treatment that a patient may need support/referral to assist with management. If a patient has another chronic disease, it may be easier to copy and paste the cancer-related sections into their existing care plan.

Best Practice - import instructions

1. Save the template file to your desktop, but avoid opening it
2. Login to Best Practice
3. Close out of patient search so you are back at the main screen with logo (bird)
4. From the main screen, either press the F4 key OR go in to 'Utilities' menu, and then into 'Word Processor'
5. A window will appear 'Bp Premier Word Processor - Untitled'
6. Go in to 'Templates' menu, and then 'Import Template'
7. Find the template on your desktop, select it and press 'Open'
8. Go in to 'File' menu, and then 'Save As'
9. A window will appear 'Template detail'
10. Give the template a name that clinicians will recognis
11. Tick the 'Available to all Users' box and press 'Save'
12. Go in to 'File' menu, and then 'Close' to take you back to the main screen
13. The template is now ready for use with a patient record.

Medical Director - import instructions

1. Save the template file to your deskop, but avoid opening it
2. Log in to Medical Director
3. Close out of patient search so you are back at the main screen with logo (clinical)
4. From the main screen, either press F8 key, OR go into 'Tools' and then 'Letter Writer'
5. Select 'Blank Template' and then press 'OK'
6. Go into 'File' and then 'Import'
7. Find the template on your desktop, select it and press 'Open'
8. Go into 'File' and then 'Save as Template'
9. Give the template a name that clinicians will recognise
10. Ensure 'All Users' is ticked, and press 'Save'
11. The template is now ready for use with a patient record.

Zedmed - import instructions

1. Save the template file to your deskop, but avoid opening it
2. Log in to Zedmed
3. Press 'Clinical Records' button (last button on left side).
4. Go to 'Tools' menu, then 'Clinical WP Setup', and into 'WP Templates'
5. A window will appear 'Template Selection'
6. Go to 'File' menu and into 'Import Template'
7. A window appears 'Template Import'- press 'Browse'
8. Find the template on your desktop, select it and press 'Open'
9. Give the template a name that clinicians will recognise
10. Press 'OK', and 'Close'
11. The template is now ready for use with a patient record.

Experiencing issues?

Contact Vitor Rocha – Palliative Care Lead at vrocha@murrayphn.org.au for support.

TRAINING AND EDUCATION

Training	Description
For more information: Quality improvement resources	• Murray PHN Focus on cancer, including: – Cancer screening quality improvement toolkit – Change idea templates – HealthPathways – Optimal Care Pathways: better cancer care – PHN Exchange • Murray HealthPathways cancer pathways • Murray PHN quality improvement resources including PDSA (Plan. Do. Study. Act) templates: – Practice Improvement Program (PIP) QI Register and Information Webinar – Quality Improvement (QI) for General Practice 2022 Handbook – PDSA Model for Improvement Template – Simplified QI Template – QI plan example – Improve chronic conditions management PDSA template (attached) • How to import the Optimal Care Pathways (OCPs) into Best Practice or Medical Director • Optimal Care Pathways web application
Follow-up guidelines	• National Comprehensive Cancer Network Guidelines: Treatment by Cancer Type
Cancer resources: Professional development	• Cancer Council: Online learning • EviQ: Introduction to supportive care in cancer (30mins) • Cancer Council Victoria: Education and online learning for GPs • Clinical Placement Program in Cancer Survivorship 2022-2024 (practice nurses and allied health): Peter Mac Murray PHN resources: • Supporting general practice • Quality improvement • Professional development (CPD) presentations
Cancer resources: Screening and care planning	• Optimal Care Pathways • EviQ: Health professional fact sheets • HealthPathways: Cancer Supportive Care • Cancer Council Victoria: Cancer support referral - If you have a patient or carer who needs support, complete the online referral and a cancer nurse will contact the patient/carer • Loddon Mallee Service and referral guide • Australian Cancer Survivorship Centre: mycareplan - Create a cancer survivorship care plan online • NCCN Distress Thermometer tool
Cancer resources: For patients	• Cancer Council Victoria: My Cancer Guide - new online cancer services directory) • Peter Mac: Common Survivorship Issues Directory - provides information and tools to support survivors to access evidence-based and quality survivorship care • Cancer Mind Care - Explore ways to look after your mind when you are affected by cancer • Cancer Survivor Guide – a podcast series that takes you through what can happen after diagnosis and treatment including surgery, chemotherapy and radiation • Peter Mac: Can-Sleep: Making night-time sleep problems go away, a guide for people with cancer

CANCER SHARED CARE

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UNDERSTANDING PALLIATIVE CARE

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and assessment, and treatment of pain and other problems - physical, psychosocial and spiritual.

End-of-life care

End-of-life care includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after their death. People are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days).

Palliative care aims to improve the quality of life of patients with life-limiting illnesses. Improving palliative care is now an Australian Government priority. The National Palliative Care Strategy (2018) and Implementation Plan (2020) provide a shared vision for the continual improvement of palliative care across services in Australia, including general practices. For more information, visit the Australian Department of Health and Aged Care and the Australian Institute of Health and Welfare palliative care webpages.

With the growth and ageing of Australia's population (nationally 16.2% [VIC state 22%] are aged 65 years and older), and an increase of chronic and life-limiting illnesses, the types of patient groups requiring palliative care has widened.

Palliative care is often linked to the care of people with cancer. However, patients with non-cancer end-stage chronic or complex conditions also have significant palliative needs.

Dementia is a good example of a non-cancer condition requiring palliative care. Among regional Victorians, it remains the second most common cause of death in the Gippsland and Murray regions and remains highly prevalent in the Grampians-Wimmera regions in Western Victoria.

The burden of symptoms and care needs for patients with end-stage, non-malignant illnesses can be similiar to the needs of patients with advanced cancer. These patients benefit from a palliative approach, comprising management of the underlying condition and attention to symptoms, psychosocial needs and carer support. Advance care planning provides an opportunity to prepare for future illness episodes, including provision of end-of-life and terminal care.

GPs are well-placed to provide palliative and end-of-life care for patients with advanced non-cancer illnesses. The role of GPs in palliative care has been endorsed by the RACGP.

More regional Victorians have written end-of-life and palliative care plans compared to metropolitan counterparts (4.2-4.4%, 2.7- 3.5%, respectively). However, this remains low in comparison to countries like Switzerland where 24% of the population reported having one.

1.1 Illness trajectories

It is important to be able to recognise a patient’s stage of deterioration, as either:

- at-risk of dying within the next 12 months
- likely to die within the next weeks to months
- dying within days.

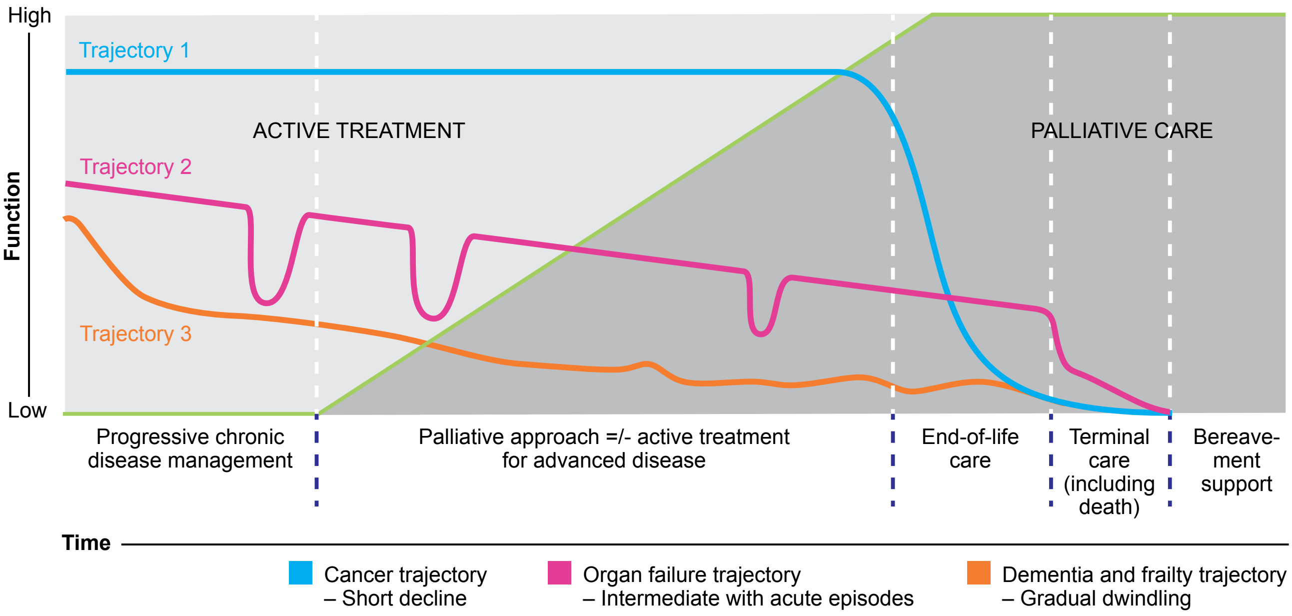
For people who are likely to die in the short-term, such as within days to weeks, it is likely that their clinical deterioration is irreversible. Identification of where they want to be for their terminal phase is a vital part of providing terminal phase care.

For people who are likely to die in the next 12 months, they may experience rapid changes and fluctuations in their condition which may be reversible. There are best practice tools than can support early identification of end-of-life patients.

The three main trajectories of illness (Figure 3 below) for people facing towards end-of-life are:

- Cancer trajectory – short decline
- Organ failure trajectory – intermediate with acute episodes
- Dementia and frailty trajectory – gradual dwindling.

Figure 3: Typical illness trajectories and palliative care phases towards the end-of-life



1.2 Advance care plan

GPs have an important role to play in both promoting and facilitating advance care planning.

GPs can support patients through the planning process, discuss any issues and provide information on the patient's health, prognosis and future treatment options.

Often having a long-term relationship with their patients, GPs are well-placed to begin advance care planning early and at opportune times in a patient's care.

Advance care planning can be introduced in general practice through:

- usual assessments and care planning, such as the 75+ Health Assessment and Chronic Disease Management planning
- routine consultations with a patient who has a chronic illness, is at risk of losing capacity, is in an aged care facility, has just received a significant diagnosis etc.
- follow-up consultations after a hospital admission.

1.3 Voluntary assisted dying

In their 2022 position statement, Palliative Care Australia notes, "it is important to recognise that voluntary assisted dying (VAD) is a separate practice from palliative care." For additional information, refer to Palliative Care Australia's position statement 2022. RACGP also discusses the role of GPs in VAD in their latest position statement. Access the position statement here.

A registered health practitioner must not initiate a discussion about VAD or suggest it to a patient. Victorians at the end-of-life who meet strict criteria can request access to it. A health practitioner may choose whether or not they participate in VAD and they must complete VAD training, via the Victorian Department of Health website, before conducting an eligibility assessment. For additional information on VAD refer to Voluntary Assisted Dying Act 2017.

1.4 Mental health and wellbeing considerations

There is a recognised impact on the mental health of people with palliative care needs, as well as it being part of the presentation of many conditions. Therefore, a thorough assessment of mental health is essential in determining the best approach to care.

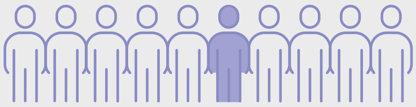
A number of assessment scales and tools are available to assist in this and include:

- Geriatric Anxiety Inventory (GAI) - validated for use in older people in residential facilities
- Rating Anxiety in Dementia scale (RAID) - used and validated with dementia patients in different settings and is commonly used as an anxiety measure in residential aged care facilities (RACF)
- Initial Assessment and Referral-Decision Support Tool (IAR-DST) - an online diagnostic tool for the initial assessment and referral of individuals presenting with mental health conditions in primary healthcare settings. This tool may be helpful in assessing the suicide risk of patients diagnosed with a life-limiting illness who are experiencing distress and/or have other risk factors such as an existing mental health condition.

1.5 Carer perspective

Carers make up a fundamental part of healthcare, specifically during the end-of-life. They provide ongoing support, mostly unpaid, to others living in the community with chronic illness, progressive or incurable conditions, frailty, dementia and disability. Often, people who perform caring duties don't consider themselves as carers, and less frequently access general practice services to manage their own healthcare needs or to ask for help and support in their caring role.

Another important group of carers are those aged 25 years and under who have a level of caring responsibility of an adult, and often dismiss their own health and important activities, such as attending school and work, to care for their family member or friend.



One in 10 Australians (2.65 million) are carers

Carers are three times more likely to experience social isolation and loneliness compared to the average Australian

Carers are exposed to an increased incidence of psychological distress, anxiety, depression and are prone to caregiver burnout and compassion fatigue

In Victoria, more than 730,000 people are carers

11% of Victorians

25% provide 40+ hrs unpaid care/week

70% are Female

10% are younger than 25 yo

239,000 Australians are primary carers. Defined as the primary person responsible for providing assistance to one or more people who need assistance with core activities related to mobility, self-care and/or communication

Carers are more likely to experience financial hardship (income of 42% lower than a non-carer)

Carers are less likely to have health and support services nearby if in rural and regional areas, but report stronger social networks

Diverse communities

1.6 First Nations communities

A respectful approach to palliative care for Aboriginal and Torres Strait Islander people is one that acknowledges individual preferences, values, beliefs and cultural heritage. There are cultural sensitivities surrounding death and it is important that an individual's palliative and end-of-life care journey includes care that is responsive to cultural beliefs and practices. **Many Aboriginal and Torres Strait Islander people might not engage in discussions about future medical care, which can be considered 'family business,' not to be discussed outside the family unit**. In some Aboriginal and Torres Strait Islander communities, the topic of death is considered taboo. Health professionals should be encouraged to seek consent to talk to Aboriginal and/or Torres Strait Islander health workers, or consent from the person's family for help where possible.

Past Australian government policies and actions have resulted in loss of connection from Country, family and culture for Aboriginal and Torres Strait Islander Peoples. Mistrust in the healthcare system and its staff can result in misunderstanding or fear of palliative care service providers, with a reluctance to access supports available to individuals and their family. Journey to Dreaming resources are available to support these conversations.

1.7 Culturally and linguistically diverse communities (CALD)

Multicultural and multifaith communities (also described as culturally and linguistically diverse communities [CALD]) have different perceptions, beliefs and relationships with death and dying. When discussing palliative care with multicultural and multifaith patients, their cultural beliefs, spirituality (linked or not to a religion), carers, families and communities need to be considered.

It is important to be mindful that these communities are more likely to experience multiple social disadvantages and have poorer health outcomes, due to the stigmatisation and/or marginalisation of their culture, language, physical characteristics and residency status.

Also, religious and cultural beliefs vary between individuals, even in close family units. For example, this may impact the acceptance of blood or blood products, organ donation, resuscitation, handling of the body just before or after death, and transfer to the mortuary or coroner.

Keep in mind that the primary source of information regarding death and dying practices in multicultural and multifaith communities is the patient and/or the family themselves.

They should be consulted about culturally appropriate methods to discuss their wishes and goals at the end-of-life to prevent assumptions.

English language barriers can also create culturally unresponsive interactions and challenges when discussing palliative care. In this scenario, consider use of the Translating and Interpreting Service.

1.8 LGBTQIA+

Many lesbian, gay, bisexual, transgender, queer/questioning, intersex and asexual (LGBTQIA+) people have experienced discrimination and/or other negative experiences when accessing healthcare services because of their sexual orientation, gender and/or sex characteristics. Additionally, this community has been historically stigmatised for their gender expression and family structure. For LGBTQIA+ people, palliative care may be a particularly difficult conversation as commonly their partner/s and other significant people are not recognised as family. Their biological family may be estranged or not involved in their life, and sometimes linked to previous traumatic experiences. They may also be concerned that someone other than their chosen person/people may step in, and make decisions when their condition deteriorates. Therefore, asking about their chosen family is important to establish a trustworthy relationship and start honest conversations about their wishes and goals at the end-of-life.

Gender affirming language reinforces LGBTQIA+ peoples gender expression and safety.

Assuming a patient is LGBTQIA+ doesn't mean you have to specifically ask if they are; it means that you ensure your language is inclusive. A good example is asking for their preferred pronouns instead of assuming them.

It is important that we advocate for LGBTQIA+ people to have their decisions formally recognised through power of attorney and advanced care directive documentation.

1.9 Disability

People living with disability have the right to quality care and to make decisions about their medical treatment. For individuals with a life-limiting illness who have a disability, advance care planning conversations should be part of routine quality care.

APPENDIX 10

CANCER SHARED CARE

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EARLY IDENTIFICATION OF PATIENTS REQUIRING PALLIATIVE CARE

Best practice tools to support early identification of palliative patients

Surprise question

The surprise question is a simple trigger that prompts clinicians to ask themselves, ‘Would I be surprised if this patient died in the next year?’

If the answer is ‘No’, it should prompt the clinician to:

- recognise that their patient is at risk of deteriorating and dying, and
- offer and discuss advance care planning, or revisit their previous advance care plan, and
- refer their patients to specialist palliative care for a thorough assessment if required, OR
- consult specialist palliative care for advice.

For more information, refer to the health.vic webpage, The last twelve months of life and Australian Government Department of Health and Aged Care webpage, GP best practice research project.

Supportive and Palliative Care Indicators Tool (SPICT™)

SPICT is a free, online and evidence-based clinical tool used in many countries to help clinicians identify people at risk of deteriorating due to advanced, progressive or life-threatening conditions.

The tool has three domains that provide guidance on:

- identifying the type of general indicators for poor or deteriorating health
- identifying clinical signs for the different types of life-limiting conditions
- prompting for review and assessment of people’s needs and care planning earlier.

The tool can help clinicians decide when it is time to start a conversation with people about their health and care, including what is important to them and the available treatment and care options.

For more information, visit the SPICT website.

Training and education is available as part of The Advance Project.

The tool is designed to look at health status, not prognostic timeframe, because it is not possible to know exactly when a person will deteriorate or die. It is important to refer everyone who is at risk of deterioration for early assessment and care planning.

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IMPORTANT CONVERSATIONS AND ADVANCE CARE PLANNING

Important conversations and advance care planning

Embedding early discussions is pivotal in a patient's palliative care. Patients can then plan their healthcare and what they want for the rest of their life. The amount of information a patient will want to hear will vary.

Starting a conversation about dying can be challenging, but not as difficult as trying to initiate this discussion when someone is entering their terminal phase. Some patients or patients' relatives may initiate discussions with you, and it's best to be prepared.

Advance care planning

Advance care planning is a process of discussion and reflection on values and wishes regarding future healthcare choices. In Victoria, this is supported by the Medical Treatment and Planning Act (2016) which sets out how people can record who they want to make healthcare decisions for them if they lose capacity (medical treatment and decision maker) and what they want known about their wishes about future healthcare (Values Advance Care Directive) or any instructions they want their doctor to know (Instructional Advance Care Directive). Some definitions may differ within NSW - see NSW Health for more information.

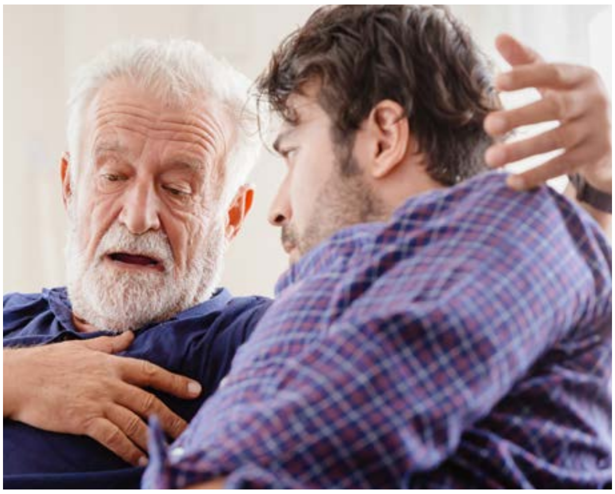
Advance care planning documents are only to be used if a person is unable to make or communicate their decisions. People can change their mind, their plans, their Statement of Choices and legal documents at any time while they have decision-making capacity to do so.

Facts about advance care planning

The benefits of advance care planning include:

- improves caregiver satisfaction while reducing psychological burden
- positive impact in ambulance and hospital use, especially emergency departments
- improved patient emotional status
- potential to avoid patient suffering at the end-of-life due to anticipatory care management.

The issue is mentioned in the final report of the Royal Commission into Aged Care Quality and Safety (2021) and discusses the importance of cross-sector implementation of advance care planning in routine practice, and review of the Aged Care Quality Standards to embed advance care planning discussions as priority for future better care outcomes of those living with life-limiting illnesses.



Considerations for diverse communities

First Nations

When introducing advance care planning to Aboriginal and Torres Strait Islander Peoples, allow adequate time to provide a clear explanation of the benefits to the individual, family and community. Approach difficult conversations gently and revisit the conversation at another time if needed. Respect the person's right to not discuss these issues with you. Avoid making assumptions about the roles and relationships of family members (e.g. carer, decision maker, advocate). Complex cultural issues may be involved in who takes which role and when.

Many Aboriginal and Torres Strait Islander people have a strong connection to their land and Country and may be distressed if they need to move into care, away from their community. Documenting their preference to stay on Country may be an important aspect of their advance care planning.

Advance Care Planning Australia has excellent resources for care planning with Aboriginal and Torres Strait Islander Peoples. Gwandalan is comprehensive resource for education and training to support palliative care for Aboriginal and Torres Strait Islander Communities, with extensive information on advance care planning.

Culturally and linguistic diverse (CALD)

For patients with varying levels of English literacy, use the Translator and Interpreter Service. This tool is available online and allows you to translate appointment details into your patient's language. It is equally important to consider cultural safety for non-English speaking patients. For information and training, visit the ceh.org.au website.

Palliative Care Victoria has a number of translated general factsheets about palliative care.

North Western Melbourne PHN has developed a number of translated brochures about roles and responsibilities in advance care planning - available in Arabic, Chinese (Simplified), Chinese (Traditional), English, Greek, Italian, Macedonian, Turkish and Vietnamese.

LGBTQIA+

There are several more challenges for LGBTQIA+ people engaging in advance care planning. Commonly, they don't know about the legal options available to protect their end-of-life wishes and often healthcare professionals are not aware of LGBTQIA+ peoples' chosen family structure.

Practical tips for healthcare professionals:

- Consider that every patient you meet could be LGBTQIA+ and may have been subject to harm and discrimination in the healthcare system.
- Don't assume that a person's biological family are the patient's legal decision-makers, regardless of their chosen family – a term used to describe who an LGBTQIA+ person considers to be their true family and preferred legal decision-makers.
- Your LGBTQIA+ patient is the best source of information. An honest conversation about how they want to be addressed (their pronouns) and who are the important people in their lives can be a starter for advance care planning discussions.

For more information, access Advance Care Planning Australia website.

Reference: Advance Care Planning Australia. Advance Care Planning for people who are LGBTIQ+.

People living with a disability

People are presumed to have decision-making capacity in relation to matters that affect their lives, including healthcare. However, some people with a cognitive disability may not have medical decision-making capacity. In which case, the preferences that an individual may have shared in the past may play a role in decisions, or an appointed medical treatment decision maker can make medical treatment decisions on their behalf.

The Office of the Public Advocate provides specific information and advice regarding the protections and the process for medical treatment decisions of a person under guardianship.

An individual who lacks capacity to complete an Advance Care Directive, or other advance care planning documentation for themselves, may have known values and preferences for future healthcare. These can be recorded by one or more people who know the individual well, using the form, 'What I understand to be the person's preferences and values'. This form can assist an individual's medical treatment decision maker to make decisions about medical care in line with what is understood to be the individual's preferences.

It should be noted that this form is not an advance care planning document. Only documents completed by a person with decision-making capacity are advance care planning documents or Advance Care Directives.

Resources

- See the pathways available at Murray HealthPathways (Note: You will need a username and password to access Murray HealthPathways. Health professionals can request access online by clicking here)
- For information about advance care planning (including legal requirements) in your state or territory, see Create Your Plan
- Visit the following NWMPHN advance care planning links (note that all forms under the Medical Treatment Planning and Decisions Act 2016 are free to download and may be completed without seeking legal advice or assistance):
  - Roles and responsibilities in advance care planning
  - Advance care planning in residential aged care
  - Advance care planning in community health
  - Advance care planning in domiciliary nursing services
  - Advance care planning brochure: other languages order form
  - Make advance care planning part of routine care (MBS item numbers)
- Resources for people who lack capacity to undertake advance care planning:
  - 'What I understand to be the person's preferences and values'. *It should be noted that this form is not an advance care planning document. Only documents completed by a person with decision-making capacity are advance care planning documents or Advance Care Directives.
  - Resources for people who lack capacity to undertake advance care planning - Northern Health

Definitions

Advance care planning	Advance care planning involves planning for an individual's future healthcare. It enables an individual to make some decisions now about the health they would or would not like to receive if they were to become seriously ill and unable to communicate their preferences or make treatment decisions. Advance care planning involves thinking about, discussing and recording preferences for the type of care an individual would like to receive and the outcomes they consider acceptable, enabling the individual's loved ones and health providers can know and respect treatment preferences. Ideally, advance care planning will result in your an individual's preferences being documented. In Victoria, there are two ways an individual can record their choices for future medical care: • Appoint a medical treatment decision maker • Complete an Advance Care Directive
Advance Care Directive	An Advance Care Directive can include either, or both, of the following: • A values directive • An instructional directive. A values directive is a statement of an individual's values and preferences for their medical treatment. The appointed medical treatment decision-maker will use this values directive to guide them when they make decisions for the individual. An instructional directive is a legally binding statement about future medical treatments an individual consents to or refuses. An instructional directive takes effect as if the individual had consented to, or refused the treatment.
Medical Treatment Decision Maker (Vic)/ Enduring Guardian (NSW)	A medical treatment decision maker has legal authority to make medical treatment decisions on an individual's behalf, if that individual does not have decision-making capacity.
Power of Attorney	An enduring power of attorney is a legal document that allows an individual to appoint someone to make decisions about personal and/or financial matters. This person is called an attorney. The power endures if and when the individual is unable to make decisions. The attorney cannot make medical treatment decisions for the individual, unless they are also appointed the medical treatment decision maker. If an individual has appointed a medical enduring power of attorney, an enduring power of attorney, or enduring power of guardianship prior to 12 March 2018, these are still valid.