

NATIONAL GUIDANCE

Follow-up and
supportive care
of people with
lung cancer after
curative-intent
therapy

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Introduction

Lung cancer remains the leading cause of cancer death in New Zealand. Large inequities and relatively poor survival rates continue to have the greatest impact on overall cancer morbidity and mortality in New Zealand. The Atlas of Healthcare Variation (Health Quality and Safety Commission New Zealand [HQSC NZ], 2016) states:

- lung cancer accounts for nearly a third of all Māori cancer deaths
- one- and five-year survival rates remain poorer for Māori than non-Māori
- surgery, with the aim of curing disease, is the treatment of choice for patients diagnosed with early stage non-small cell lung cancer (NSCLC)
- surgical resection rates were lower for Māori (13.3 percent) than non-Māori (15 percent).

Traditionally, the person diagnosed with lung cancer and treated with curative intent are routinely followed up by the treating specialist in a hospital setting for up to five years post treatment using chest x-rays to look for local recurrence. Frequency of follow-up appointments and imaging surveillance has not been agreed nationally or internationally. There is no clinical evidence that intensive follow-up approaches based on regular laboratory and radiological investigations improve outcomes or experience in people who are asymptomatic.

In recent years there have been major advances in the understanding of the different types of lung cancer, improved and novel diagnostics and treatments, improved survival rates for certain treatments, and a better understanding of the needs of people who have been treated for cancer. This has meant that survivorship models and supportive care pathways for people who have been treated with curative intent for lung cancer need to be included in this guidance. Follow-up and supportive care as part of a survivorship model is a developing model of care.

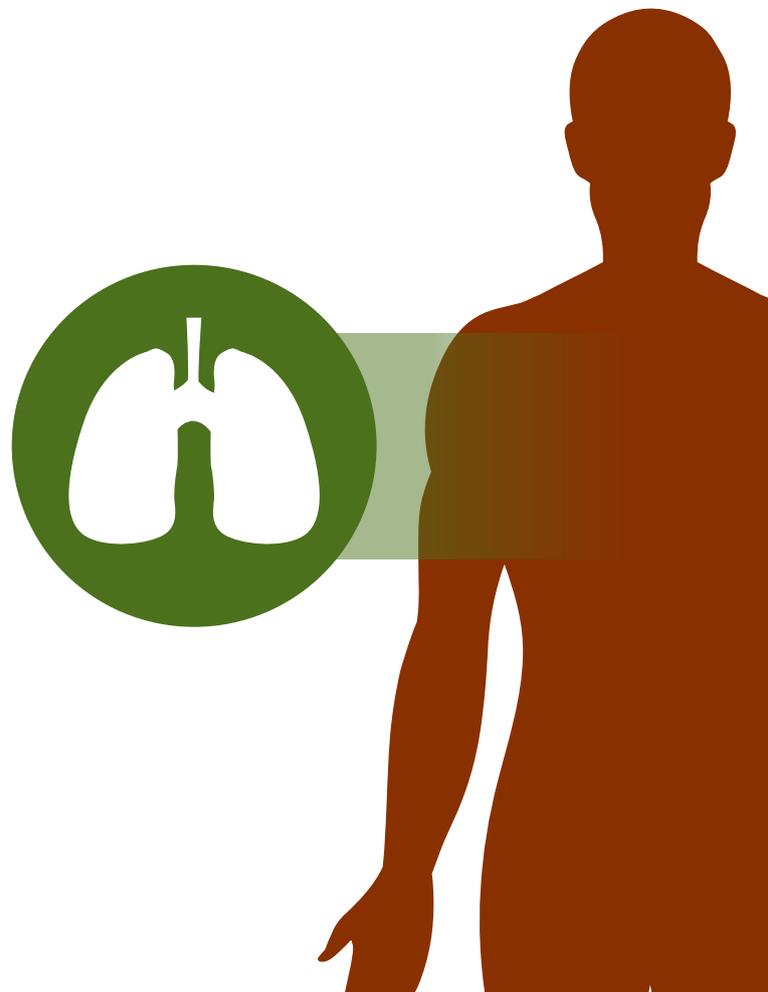
There is increasing emphasis on a whānau focus, on community services and teams being supported by those in the treating hospital. An emphasis on whānau is consistent with a person's autonomy. At each interaction, the person identifies their whānau, and consents to their particular involvement. Whānau is also described in He Anga Whakaahuru Framework as people of family descent as well as those important people who make up their support network (Central Cancer Network 2016). In this guidance, 'Whānau' is used to describe the person affected by cancer and their whānau.

The use of web-based monitoring people with lung cancer post treatment is growing in interest worldwide. There has been promising results from research in France suggesting improvement in cancer and resource utilisation outcomes (Dennis et al 2016). Application technology is advancing and offering whānau an opportunity to share knowledge, experiences and support during and following treatment. Breast Cancer NZ has already developed an online community app.

The guidance is aligned to and supports the New Zealand Health Strategy 2016 strategic themes of people-powered, closer to home, one team, smart system and value and high performance to support the health and well being of all New Zealanders.

The aims of New Zealand's Triple Aim framework, improved health and equity for all populations; best value for public health system resources and improved quality, safety and experience of care were essential considerations when developing the guidance.

Inequities in access to health services, diagnostic procedures and treatment are well known but there is less evidence around follow-up after curative treatment.



Guideline objectives

In New Zealand, there is variability around the country in the follow-up and supportive care of whānau after curative treatment of lung cancer. This document is the starting point towards supporting a nationally consistent approach to follow-up after people affected by lung cancer have completed curative-intent treatment. The objectives are to offer supportive care and to detect local or distant recurrence at an early stage so that treatment (radical or palliative) for any relapse can be started in a timely and appropriate manner.

The guidance is linked to and supports service provision in line with the Standards of Service Provision for Lung Cancer Patients in New Zealand (2016) Standard 9.1: Follow-up and Surveillance.

Intended users

The guidance applies to a person who has been affected by small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC) following curative-intent treatment by:

- surgery
- radical radiotherapy including stereotactic ablative radiotherapy (SABR)
- chemo-radiotherapy.

The intended users of the guidance are thoracic surgeons, medical and radiation oncologists specialising in lung cancer, radiologists, general practitioners, respiratory physicians, nurses, including nurse practitioners and advanced practice Registered Nurses (RNs), enrolled nurses, mental health or primary care nurses, other primary care providers, psychosocial support and palliative care providers, non government organisations and district health board funders and planners. The guidance also outlines specific follow-up and supportive care information post treatment for curative intent lung cancer for affected whānau.

Aim

The intent of the National guidance – Follow-up and supportive care of people with lung cancer after curative-intent therapy is to:

- support, educate and encourage whānau self-management and well-being options
- clarify optimal pathway following treatment including recommendations regarding follow-up and frequency of follow-up etc.
- provide information to the primary care team to support implementation of the follow-up plan
- monitor for cancer recurrence or spread at an early stage so that treatment for any relapse can be started in a timely manner
- identify appropriate key contact person to facilitate and coordinate primary and secondary/tertiary care health professionals to manage side effects, complications of treatment and referral back into the secondary/tertiary care if necessary.

Scope of guidance

This guidance covers the period prior to discharge from final curative intent treatment through to five years post treatment and includes:

- treatment summary
- follow up/recovery plan based on health needs assessment
- psychosocial and support services
- clinical care review and imaging surveillance.

A consensus approach of the expert opinion of the National Lung Cancer Working Group (Appendix D) was used to determine the appropriate timing of follow-up imaging surveillance. This has taken into account that there is little high level research or evidence as to what is the gold standard approach that is most effective either for the person affected by lung cancer or clinician.

Essential elements of the follow-up and supportive care guidance include:

- equitable access to follow-up and supportive care services
- care coordination including interagency and interdisciplinary input
- follow up/recovery care planning that offers lifestyle changes e.g. smoking cessation, immunisations, other lifestyle support services
- easy way back into system with a single point of contact
- standardised imaging
- whānau experience feedback to gauge quality of services.

Equity for Māori

He Korowai Oranga is New Zealand's Māori Health Strategy and sets the framework to achieve the best health outcomes for Māori. The strategy was refreshed in 2014 to include Pae Ora which builds on the initial foundation of Whānau Ora (Healthy Families) Mauri Ora (Healthy Individuals) and Wai Ora (Healthy Environments).

Three principles of the Treaty of Waitangi that are relevant to Māori health are:

- **Partnership** – government, iwi, hapū, whānau and Māori communities should work together to develop strategies for Māori health gain and appropriate health and disability services.
- **Participation** – Māori participate at all levels of the sector in decision-making, planning, development and delivery of health and disability services.
- **Protection** – Māori should have at least the same level of health as non-Māori whilst safeguarding Māori cultural concepts, values and practices.

An audit of lung cancer care identified that Māori were 2.5 times more likely to have locally advanced disease and four times less likely to receive curative treatment compared to Europeans (Stevens 2004, Lewis, 2012).

The Standards of Service Provision for Lung Cancer Patients in New Zealand (MOH 2016) recognises that there needs to be a focus on improving early detection, timely access to diagnosis and treatment for all people, including Māori, to increase the chance of curative intent treatment. The standards also require that whānau be involved in care coordination and supportive care. A whānau ora approach to health care recognises the interdependence of people; health and wellbeing are influenced and affected by the 'collective' as well as the individual. It is important to work with people in their social contexts, and not just with their physical symptoms. There is also a good practice point in the standards which supports health literacy and cultural competency training for all health professionals which will give the health professional a better understanding of how to interact with and empower whānau in their decision making.

In pursuit of equity for Māori, we have written this guidance with an emphasis on whānau. As clinicians working in New Zealand, we assert the value of whānau-based approaches to health care. It is very hard for a person to carry the burden of major illness on their own. Te taha whānau, the whānau aspect of health, is a cornerstone for recovery and survivorship.

Quality statements

The Quality Statement is based on the National Institute for Health and Care Excellence (NICE) Quality Statement 14, (updated March 2019) Optimal Follow up Regime.

Clinical care review

1. Specialist follow-up appointment offered within six (6) weeks of definitive treatment.
2. Documented protocol led follow-up arrangements offered in longer term either with specialist, General Practitioner (GP) or Nurse Practitioner (NP); Clinical Nurse Specialist (CNS).

Good practice points

1. Treatment summary given to all whānau appropriate to their health literacy.
2. Health needs assessment plan which may include Advanced Care Plan (ACP) developed by whānau.
3. Psychosocial needs assessment completed.

Implementation

Implementation of the guidance needs to be aligned and linked to other Ministry of Health cancer programmes that are in progress. These include:

- development of online standards of care for people affected by cancer
- tumour stream quality performance indicators.

This is the first national tumour group guidance for follow-up and supportive care. In view of this and the need to align with other national cancer programme work, the working group think it is likely that this guideline will need to be updated one year following publication.

Follow-up and supportive care guidance

Factors that influence follow-up

- **Whānau:** dynamics, priorities and preferences, co-morbidities, fragility, geographical and social isolation
- **Pathway:** expected and/or un-expected complications
- **Cancer:** histology, stage and prognosis, effectiveness of adjuvant and second line intervention and surveillance
- **Access:** availability of local versus regional resource
- **Coordination:** strong links between tertiary, secondary, primary health services and community support services

Recommendation	Minimum requirement	Lead	Outcome
<p>Treatment summary</p> <ul style="list-style-type: none"> • Primary care providers will receive a treatment summary • Whānau will receive a treatment summary appropriate for their health literacy 	<ul style="list-style-type: none"> • Primary treating specialist is responsible for completing a treatment summary • Treatment summary will include as a minimum: <ul style="list-style-type: none"> - diagnosis - all treatments received and when completed - long term side effects that may occur - whānau understand what the situation is, prognosis that has been discussed, and any advance care plan formulated. - signs and symptoms which may indicate recurrence and need for further investigation. - key single point of contact with contact details - a follow-up plan including providers/ agencies involved, frequency, and duration • A standardised format is used 	<p>Treating specialist</p>	<ul style="list-style-type: none"> • Treatment summary completed • Whānau understand the written treatment summary • GP practice or NP and whānau receive a copy of treatment summary • Treatment summary is added to electronic clinical record where available
<p>Health needs assessment (HNA) and follow-up plan</p> <ul style="list-style-type: none"> • A follow-up and support plan based on health needs assessment is developed in consultation with whānau • Whānau receive education 	<ul style="list-style-type: none"> • Holistic HNA is initiated when curative intent treatment starts • Referrals to other services as required • ACP should be initiated at the start of the cancer journey if not already in existence and revisited when developing a follow-up plan • Follow-up plan is developed in consultation with whānau and multidisciplinary team • Written information on post treatment, follow-up process and what to expect following curative treatment • Symptom recognition i.e. advice on who to contact should symptoms appear in the interval between scheduled reviews • Understands access back to secondary care • Referral to support groups • Information both hard copy and electronic given to whānau • Survivorship information • Palliative care service information as appropriate 	<p>NP, lead lung cancer nurse, or advanced practice RNs</p>	<ul style="list-style-type: none"> • Follow-up and support plan completed • ACP discussed and documented as appropriate • GP practice or NP, and whānau, receive a copy of follow-up and support plan • Whānau understand the follow-up plan • Information is in an easy to understand format



Recommendation	Minimum requirement	Lead	Outcome
<p>Psychosocial and support services</p>	<ul style="list-style-type: none"> • Psychological needs assessment, screening and appropriate referrals made • Social and support needs assessed; appropriate referral made including carer/ home support, meals, housing, finance/ welfare etc. • Cultural support needs assessed and provided as appropriate • Health promotion and wellness programmes offered including exercise programme to promote physical activity e.g. Green prescription • Counselling and stop smoking support offered • Advance care planning support offered and provided as appropriate • Immunisation schedules such as annual flu vaccination outlined and provided 	<p>Supportive care team e.g. psychologist / social worker / counsellor</p> <p>Social worker</p> <p>Stop smoking practitioners</p> <p>Primary care provider</p>	<ul style="list-style-type: none"> • Psychosocial needs assessment completed • Support systems are in place • Whānau have contact information for support services
<p>Clinical care review</p> <ul style="list-style-type: none"> • Undertaken at initial post treatment appointment • Imaging surveillance <p>Surveillance and imaging modality specific to symptoms</p>	<ul style="list-style-type: none"> • Medical history, physical exam and imaging as determined by treating specialist <ul style="list-style-type: none"> - Surgery – at least one clinic visit post discharge to assess for surgical complications - Medical oncology – if chemotherapy as part of chemo-radiotherapy given post-surgery - Radiation oncology – if at least one radiation treatment is given - General or respiratory physician – any ongoing significant medical or respiratory co-morbidity • Chest x-ray at three months post treatment specialist review • Additional imaging should be based on symptoms and signs and not routine. Small number of patients may benefit from CT follow up, see imaging section (page 9) 	<p>Treating specialist initial review</p> <p>Ongoing follow-up by GP, NP, or advanced practice RN's</p> <p>Treating specialist to order (refer follow-up template)</p>	<ul style="list-style-type: none"> • Whānau attend post treatment appointment • Plan for further follow-up is confirmed • Follow-up tests done prior to appointment

Key principles underpinning the guidance

Coordination of follow-up

Follow-up should be an agreed plan between whānau and clinician who initiated the curative-intent therapy for the primary lung cancer. International guidelines generally recommend that follow-up should be coordinated by a community and hospital based multidisciplinary team.

At the initial post treatment follow-up, a lead contact person to coordinate care with the community team should be identified. It may be a respiratory/general physician or NP, clinical nurse specialist or other advanced registered nurse. A “shared care” approach to follow-up is an integral part of ongoing care of whānau.

Most people affected by chronic conditions have a named GP who they consult regularly. The GP and their practice team (may include a NP and /or registered nurse) have an essential role in the supportive care of whānau affected by cancer. This includes knowledge of the individuals involved, their support structures and local community providers who offer support services. The general practice team provides a holistic approach to the care of whānau assessing and managing their physical and psychological social and spiritual needs.

Following treatment, the primary care provider, usually the GP, will receive a discharge letter from the secondary or tertiary care service. This letter should include details of the hospital treatment and the ongoing treatment plan (page 16). The GP or NP should assess the whānau needs and discuss any concerns or issues they may have.

There is evidence to suggest that follow-up led by a nurse provides an acceptable, appropriate and effective service to people affected with lung cancer with no difference in survival or time to progression compared to the control group. Supportive care should include specialist nursing support and access to community or District Health Board (DHB) provided psychosocial and specialist psycho-oncology services to support whānau post treatment. Nurse led follow-up is associated with cost savings and higher whānau satisfaction. On-going communication and updating of care plans is an important part of a shared care approach after treatment for lung cancer.

Virtual follow-up has the potential to be utilised for whānau who choose this option to receive services in the home rather than travel to clinic appointments either at hospital or GP clinic.

To support a consistent and coordinated approach to follow-up and supportive care, web based software tools such as Community Health Pathways are

available to primary care providers to guide whānau into secondary care. These pathways could be extended to support primary care decision making around follow-up and supportive care after curative treatment for lung cancer, and should be localised for each DHB region.

It is important that tertiary, secondary and primary health care teams have:

- appropriate guidelines for routine management after curative treatment of lung cancer
- clear communication from all of those who are seeing the whānau during their journey and
- direct access to the specialist team via a single point of contact.

Equity and health literacy

Equitable and accessible follow-up and supportive care can be achieved if there is consistency throughout the country, both in terms of location and cost. How and when follow-up occurs should be based on the particular needs of whānau and agreed between them and the treating clinician.

Health inequalities affect a range of population groups including Māori, Pacifica, low socio-economic, low income workers, rural, elderly, disabled, migrants, refugees, those with poor English language skills, and those living in specified localities.

Addressing equity particularly for Māori is dependant on all health providers being cognisant of the intent and implementation of frameworks such as Equity of Health Care for Māori: A framework, He Korowai Oranga frameworks and the Health Literacy Framework. The Equity of Health Care for Māori: A framework guides the New Zealand health sector on key actions that can be taken by: the health system; health organisations and health practitioners to achieve equitable health care for Māori.

Working closely with whānau and their preferred primary health provider, identifying at risk whānau prior to discharge, utilising Māori health models and providing culturally appropriate care are some of the strategies that can be used so equity of service provision is realised.

Research on health literacy has shown that the health care system is poorly comprehensible to a majority of Māori. The term “health literacy” is problematic, as it locates the failing in whānau, rather than in the system itself. The system carries the responsibility for improvement, because it holds the balance of power and knowledge. Health practitioners are responsible for making sure that appropriate information is provided in a way that makes sense to whānau. Follow-up plans should be simple and clear for people to understand.

The community pharmacy training package developed for New Zealand's Health Quality and Safety Commission identified three steps to better comprehension as:

Step 1 – Find out what people know

Step 2 – Build health literacy skills and knowledge

Step 3 – Check you were clear (and, if not, go back to Step 2).

Frequency of follow-up

While some cancers have evidence supporting specific follow-up regimes, others lack supporting evidence to show regular follow-up improves survival. The magnitude of the change in a person's outcome, needs to be clearly defined and considered.

Follow-up should be safe and not cause undue risk for no additional benefit. The amount of radiation that a cancer survivor is exposed to should be limited to the minimum that may help identify treatable recurrence, metastases or second primary cancers. The availability of culturally safe follow-up services is important to support whānau when they engage with health providers.

Health workers should have access to appropriate health care resources and tools to provide the necessary follow-up and supportive care services. In our resource-limited environment equitable access to resources is essential.

In both NSCLC and SCLC, the majority of recurrences are diagnosed in the first two years following curative treatment. More intense follow-up schedules do not result in overall increase in survival time.

Follow-up and supportive care should be based on specific whānau needs. Quality of life expectations and a range of other factors may determine whether a person wants to pursue ongoing vigorous treatment if there is recurrence of cancer.

For all whānau, initial follow-up clinic appointment by treating specialist should be at 6 weeks post treatment to assess for complications.

Follow-up after five years needs to be undertaken in collaboration with whānau and the primary care team.

Imaging surveillance

There is a lack of evidence for or against the routine use of imaging following radical treatment leading to improved experience of outcome for the person affected by cancer. American Society of Clinical Oncology (ASCO) guidelines specifically state that there is no proven value for either chest x-ray or CT in surveillance and therefore advocates imaging only upon the development of symptoms. Guidelines from other organisations recommend periodic chest imaging.

The Standards of Service Provision for Lung Cancer Patients in New Zealand: 2nd edition (2016) discourages routine testing beyond a plain chest X-ray in asymptomatic people with a view to free up resources for and reduces delays in diagnosing new cancers. The 2011 UK NICE guidelines have a similar approach.

Although routine imaging is not recommended, more intensive clinical and radiological follow-up including CT may be recommended for a small number of people

- people with an indeterminate lung nodule on the pre-treatment imaging who would be suitable for 2nd line radical treatment with good residual lung function and performance status
- emerging area of early stage lung adenocarcinomas in people where there may be synchronous lesions
- people with known mutation who may be suitable for targeted therapy.

In units introducing new techniques (e.g. SABR) there may be a need to have a more intense CT based serial follow-up imaging program as part of the quality assurance program. It would be an expectation that people are fully aware of this.

People may request scans in pursuit of a sense of reassurance. It is important for people to know that all imaging technology carries risks (e.g. radiation exposure), and no technology is fully accurate. Any test done in the absence of clinical suspicion will have reduced positive predictive value, meaning that positive results are more likely to be false positive. A false positive result is likely to lead to further rounds of invasive tests and treatments before the error is revealed. Even a true positive result can be harmful, in the event of premature exposure to toxic treatment that might otherwise have been able to be delayed.

People with new symptoms or signs of lung cancer should have prompt access to appropriate imaging.

Survivorship

Cancer survivors can face post treatment challenges to physical health, finances, relationships, emotions, identity and future prospects. There are various survivorship models aimed at supporting whānau post treatment around the themes of shared care, survivorship care plans, and supported self management intervention (Cancernet April 2016).

Basic survivorship care plans include the following:

- summary of cancer diagnosis and treatment
- recommendations for specific action to monitor for recurrence and secondary cancers
- information about possible long-term late effects of treatment
- advice for living a healthy lifestyle
- who will follow-up
- psychosocial and support services
- whānau information resources.

A Cancer Survivorship in New Zealand – Consensus Statement has been developed that focuses on maximising quality of life for people affected by cancer, from diagnosis through and beyond cancer. Ensuring whānau needs are assessed and addressed is a key element of the survivorship model (link below).

<https://wellington.cancernz.org.nz/about-us/news-and-media/news/survivorship-consensus-statement-published/>

The Australian Cancer Survivorship Centre in collaboration with Peter MacCallum Cancer Centre and the Victorian Department of Health and Human Service has developed a toolkit designed to support healthcare professionals and provide practical guidance to developing and implementing survivorship care plans (link below).

https://www.petermac.org/sites/default/files/media-uploads/ACSC_Survivorship_Care_Plan_toolkit_Jan_2016.pdf

Supportive care

An Implementation Plan for the Guidance for Improving Supportive Care for Adults with Cancer in New Zealand 2011 defines supportive care as: ‘the essential services required to meet a person’s physical, social, cultural, emotional, nutritional, information, physical, spiritual and practical needs through their experience with cancer’. Priority areas identified in the supportive care guidance are: care coordination, information support and psychosocial support.

This guidance recognises the importance of supportive care in the follow-up phase after completed curative treatment for lung cancer.

In July 2015, the Ministry of Health funded six clinical psychologist positions for each cancer centre as well as up to 20 FTE cancer psychological and social support workers as part of the Cancer Psychological and Social Support Initiative. Each DHB now has psychosocial support services specifically for people with cancer. In the central region, He Anga Whakaahuru – A Supportive Care Framework has been developed and adopted as a resource by the four regional cancer networks (link below).

https://www.centralcancernet.org.nz/page/pageid/2145884630/He_Anga_Whakaahuru

Palliative care

As people live longer, there will be more people with complex conditions who will need palliative care according to their individual needs to give them the best possible quality of life before they die. Some treatments given are aimed at improving quantity of life and palliative care services can support and optimise a person’s quality of life. The Review of Adult Palliative Care Services in New Zealand (Ministry of Health 2017) has prioritised five areas for action:

- increase emphasis on primary palliative care
- improve quality in all settings
- grow the capability of informal carers in communities
- respond to the voices of people with palliative care needs and their whānau
- ensure strong strategic connections.

Information links

Advance Care Plan website link

<https://www.hqsc.govt.nz/our-programmes/advancecareplanning/publications-and-resources/publication/3220/>

Last days of life link

<https://www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life>

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APPENDICES



Appendix A

Example of packages of care for follow-up and supportive care

Patient details and treatment	Tumour	Whānau preference	Recommendations
<p>67 year old male</p> <p>Right upper lobe cancer treated by lobectomy.</p> <p>Declined adjuvant treatment following discussion with medical oncologist.</p> <p>Good performance status and no significant co-morbidity.</p>	<p>Stage T2a, N0, M0</p> <p>Adenocarcinoma, EGFR mutation positive</p>	<p>Would want to know recurrent cancer if detected and would consider further treatment. Seeking advice on complementary health measures.</p>	<p>Predominantly community based follow-up. Encouraged to connect with integrative medicine practitioner. CT imaging and Hospital based single clinical follow-up at 18 months.</p>
<p>55 year old female</p> <p>Left upper lobe wedge resection for slowly growing semi solid nodule after one year surveillance.</p> <p>Two small sub 10 mm ground glass opacities in right upper and lower lobes appear stable.</p> <p>Good performance status and residual lung function, some post thoracotomy pain.</p>	<p>Stage T1b, N0, M0</p> <p>Adenocarcinoma, EGFR mutation negative</p>	<p>Would consider further surgery. Concern raised about “letting air in” and risk of cancer spread.</p>	<p>Shared community based and Respiratory follow up. Linked in with lung cancer survivor support network e.g. Lung Foundation New Zealand.</p>
<p>73 year old male with COPD</p> <p>Left upper lobe nodule initially watched, treated with SABR with no pathological diagnosis.</p>	<p>Stage T1b, N0, M0</p>	<p>Ongoing shortness of breath.</p> <p>Some differing views, leading to acceptance of patient priority of quality rather than longevity. Lives remote setting.</p>	<p>Community based follow-up including early conversation about advanced care planning, may include specialist support from palliative care. Plan in place to move in to son’s house at time of reduced independence.</p>

Appendix B

Checklist for patient and whānau affected by lung cancer

Aspect of care	What to check/do																											
Letter from hospital	<table border="0"> <tr> <td>Yes</td> <td>No</td> <td></td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Discharge letter from hospital should include: diagnosis, stage of disease and treatment received</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Letter should also include treatment plan going forward</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Key contact e.g. cancer nurse specialist, oncologist etc.</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Follow-up imaging (x-ray, CT, MRI) and pathology – check who is organising and will action the results and inform the patient</td> </tr> </table>	Yes	No		<input type="checkbox"/>	<input type="checkbox"/>	Discharge letter from hospital should include: diagnosis, stage of disease and treatment received	<input type="checkbox"/>	<input type="checkbox"/>	Letter should also include treatment plan going forward	<input type="checkbox"/>	<input type="checkbox"/>	Key contact e.g. cancer nurse specialist, oncologist etc.	<input type="checkbox"/>	<input type="checkbox"/>	Follow-up imaging (x-ray, CT, MRI) and pathology – check who is organising and will action the results and inform the patient												
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History from whānau	<table border="0"> <tr> <td>Yes</td> <td>No</td> <td></td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Health professional should check whānau understanding of diagnosis, treatment and ongoing plan</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Check on issues such as pain, worries about treatment and their side effects and the impact of cancer on their general well-being.</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Encourage whānau to initiate follow-up appointments between scheduled visits in the event of symptoms</td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Check on whānau view of involvement of hospice/palliative care</td> </tr> </table>	Yes	No		<input type="checkbox"/>	<input type="checkbox"/>	Health professional should check whānau understanding of diagnosis, treatment and ongoing plan	<input type="checkbox"/>	<input type="checkbox"/>	Check on issues such as pain, worries about treatment and their side effects and the impact of cancer on their general well-being.	<input type="checkbox"/>	<input type="checkbox"/>	Encourage whānau to initiate follow-up appointments between scheduled visits in the event of symptoms	<input type="checkbox"/>	<input type="checkbox"/>	Check on whānau view of involvement of hospice/palliative care												
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Medication	<table border="0"> <tr> <td>Yes</td> <td>No</td> <td></td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> <td>Check current medications</td> </tr> </table>	Yes	No		<input type="checkbox"/>	<input type="checkbox"/>	Check current medications																					
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Physical examination	<p>Perform:</p> <input type="checkbox"/> General physical examination including respiratory system, surgical sites etc.																											
Co-morbidities	<p>Perform:</p> <input type="checkbox"/> Check co-morbidities are recorded and treatment for cancer not interfering with management of co-morbidities <input type="checkbox"/> Assess need for specialist referral																											
Whānau involvement	<p>Perform:</p> <input type="checkbox"/> Check on key contact person <input type="checkbox"/> Concerns within whānau about wellbeing of other members																											
Psychological support	<p>Perform:</p> <input type="checkbox"/> Check for depression e.g. HADS-D, PHQ9 etc. <input type="checkbox"/> Anxiety <input type="checkbox"/> Ask about suicidal thoughts (most lung cancer patients commit suicide in six months following diagnosis)																											
ACP	<p>Perform:</p> <input type="checkbox"/> Does patient have an advance care plan <input type="checkbox"/> Does this include power of attorney																											

Appendix C: Templates

Template 1 – Treatment summary

The treatment summary must be completed with a health needs assessment and follow-up plan.

Person's name	Phone:	
	Address:	
GP name	Medical Practice contact details	
Name of treating specialist(s)	Nurse Practitioner; Cancer nurse specialist/ coordinator	
	Phone:	
	Email:	
Tests done		
Biopsy <input type="checkbox"/> Bronchoscopy <input type="checkbox"/> EBUS <input type="checkbox"/> CT biopsy		
Imaging <input type="checkbox"/> Chest x-ray <input type="checkbox"/> CT <input type="checkbox"/> PET-CT <input type="checkbox"/> MRI		
Other		
Diagnosis	Diagnosis date (dd/mm/yy)	Cancer stage
Treatment plan discussed at Multidisciplinary meeting: <input type="checkbox"/> Yes <input type="checkbox"/> No		
If not discussed at MDM, please explain:		
Treatment aim: <input type="checkbox"/> curative <input type="checkbox"/> non-curative		
Referred to: <input type="checkbox"/> Surgery <input type="checkbox"/> Medical oncology <input type="checkbox"/> Radiation oncology <input type="checkbox"/> Palliative care		
Summary of treatment and relevant dates:		
Follow-up plan has post treatment appointment details? <input type="checkbox"/> Yes		
Possible treatment long term effects		
Signs and symptoms that require referral back to specialist team:	Contacts for re-referrals or queries:	
	In hours:	
	Out of hours:	
Treatment summary completed and explanation given by:		
Completing clinician: _____ Signature: _____ Date: (dd/mm/yy) _____		
Recommended actions:		

Please take this document and your follow-up plan with you to your GP practice appointment where your diagnosis and cancer care will be reviewed with you.

Template 2 – Treatment summary letter

Date: <insert date>

Dear <insert Health Professional name>

Re: <insert person's name>

Mr/Mrs/Ms <insert name> has had the following diagnosis and treatment for cancer and has completed a whānau-oriented health needs assessment and received a follow-up plan (attached). They have been offered/received a copy of this summary.

Diagnosis:

Date of diagnosis:

Tests done:

Staging:

Treatment aim:

Summary of treatment and relevant dates:

Possible treatment toxicities and/or late effects:

Signs and symptoms that require referral back to specialist team:

Contact for re-referrals or queries:

Follow-up and ongoing management plan: (tests, appointments attached)

Recommended actions: (e.g. medication, osteoporosis/cardiac screening)

Yours sincerely

<insert clinician's signature>

<Insert clinician's name>

CC: <Insert person's name>

Please take this document and your follow-up plan with you to your GP practice appointment where your diagnosis and cancer care will be reviewed with you.

Template 3 – Health needs assessment (whānau to complete)

Goals – our goals are to:

Quality of life – we want to be able to: (e.g. work, travel, garden, sporting activities, whānau)

We want to keep healthy and need advice around:

Exercise Nutrition Smoking Support groups

What are the side effects of treatment and signs/symptoms that we should be aware of? Who should we contact if we are worried?

(To be completed by advanced practice RN in discussion with whānau)

Information

We want to know more about this type of cancer Yes No

Concerns – other concerns we have about cancer and treatment are: (e.g. body image, fertility, emotional health, sexuality, whānau reaction, work)

Support – we would like someone to help us to:

Template 4 – Follow-up and supportive care plan

(nurse practitioner or advanced practice RNs to complete with whānau)

Plan created by: _____ Date: (dd/mm/yy) _____

Agreed with whānau: _____ Date: (dd/mm/yy) _____

Follow-up checklist	Yes	No	Not needed
Follow-up clinic appointment confirmed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Repeat blood tests form given	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Histology discussed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Imaging tests discussed and requested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Referrals to support agencies completed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advance care plan completed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information resources provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Signs and symptoms to look out for discussed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Copy of treatment summary and follow-up and supportive care plan given to whānau	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Follow-up with treating specialist 6 weeks 3 months 6 months

Planned follow-up appointments

Please contact the hospital outpatient clinic <insert phone number> if you are unable to make the appointment to arrange an alternative date.

Date (dd/mm/yy)	Time	My appointment is with	Location	Tests to be done prior to follow-up appointment
E.g. 11/11/18	10am	Name of specialist	Outpatient clinic	CT chest

Medications/medicines/tablets

We understand the list of medicines and why they need to be taken. If we have queries we can contact:

Name: _____ Phone: _____

Medication	Strength	What is it for?	How much do I use and how often?	Date started (dd/mm/yy)	When do I stop taking it or get it reviewed?
E.g. Paracetamol	500mg tablets	Pain relief	2 tablets every 6 hours	01/11/2018	01/02/2019

Supportive care

You have been referred or are already receiving support from:

Service	Yes	No	Arranged by	Date (dd/mm/yy)
District nurse	<input type="checkbox"/>	<input type="checkbox"/>		
Social worker	<input type="checkbox"/>	<input type="checkbox"/>		
Dietitian	<input type="checkbox"/>	<input type="checkbox"/>		
Clinical psychologist	<input type="checkbox"/>	<input type="checkbox"/>		
Cultural support	<input type="checkbox"/>	<input type="checkbox"/>		
Pastoral care	<input type="checkbox"/>	<input type="checkbox"/>		
Benefits/advice service	<input type="checkbox"/>	<input type="checkbox"/>		
Home help	<input type="checkbox"/>	<input type="checkbox"/>		
Hospice	<input type="checkbox"/>	<input type="checkbox"/>		
Cancer Society	<input type="checkbox"/>	<input type="checkbox"/>		
Smoking cessation	<input type="checkbox"/>	<input type="checkbox"/>		
Green prescription	<input type="checkbox"/>	<input type="checkbox"/>		

Link to other care plans: <https://www.healthnavigator.org.nz/healthy-living/self-care/care-plans-action-plans/>

Notes

Follow-up may be shared between your specialist, your GP and nurse. The main aim of your follow-up and supportive care is to make sure that if necessary we pick up any further cancer at an early stage and treat you as quickly as possible. We also want to see how you are doing, to discuss any ongoing side effects, and talk about any issues or concerns you may have.

Some questions that may be helpful when talking about follow-up plan with your doctor/nurse:

1. Am I ok? Can you explain what 'ok' means?
2. How often will I need follow-up tests?
3. What will my follow-up tests involve?
4. Where should I go for my follow-up tests?
5. Who will tell me the results? When do I get my results?
6. Who should I contact if I have questions between follow-up appointments?
7. Are there any problems or symptoms I should watch out for?
8. Who should I tell if I notice a new symptom?
9. Who can I talk to about how I'm feeling and any other problems that might arise?
10. Is there a recommended exercise programme I should be doing?
11. Can I use some technology device e.g. skype, zoom, phone to connect with my specialist for my follow appointment?
12. Will I have to pay follow-up costs if I go to my GP rather than at the hospital?
13. Is it possible to talk to someone who has had a similar experience to me?

Information and support services



Cancer Society NZ

Available to support all people with any type of cancer. There are multiple services, support groups, transport, programmes, resources and tools available to health practitioners and whānau.

Cancer information helpline: 0800 226 237

Lung cancer information

<https://waikatobop.cancernz.org.nz/search/SearchForm?Search=lung+cancer>

Impact of lung cancer

<https://waikato-bop.cancernz.org.nz/cancer-information/cancer-types/lung-cancer/the-impact-of-lung-cancer/>

After treatment

<https://wellington.cancernz.org.nz/search/SearchForm?Search=getting+on+with+life>



Lung Foundation NZ

Available to support all people with any type of cancer. There are multiple services, support groups, transport, programmes, resources and tools available to health practitioners and whānau.

Contact number: 021 959 450

lungfoundation.org.nz



Health Navigator

Provides health information and links to many other websites.

Healthline: 0800 611 116

healthnavigator.org.nz



Healthpoint

Healthpoint provides up to date information about healthcare providers, referral expectations, services offered and common treatments.

healthpoint.co.nz



Work and Income

Financial support with temporary benefits if applicable.

workandincome.govt.nz/eligibility/lost-job/health-condition.html



Regional cancer networks

shared support service to DHBs.

Bay of Plenty, Hauora Tairāwhiti, Lakes and Waikato DHBs
midlandcancernetwork.org.nz



Auckland, Counties Manukau, Waitemata and Northland DHBs
northerncancernetwork.org.nz



Capital and Coast, Hutt Valley, Hawkes Bay, Mid Central, Taranaki, Wairarapa, Whanganui DHBs
centralcancernetwork.org.nz



Canterbury, South Canterbury, Southern, West Coast DHBs
www.sialliance.health.nz/our-priorities/southern-cancer-network



Hospice NZ

Goal is to help people make the most of their lives: to live every moment in whatever way is important to them.

www.hospice.org.nz/resources/a-guide-for-carers



Quitline

If you're ready to quit smoking, Quitline is ready to help.

Freephone 0800 778 778 or text 4006
quit.org.nz

Appendix E

National Lung Cancer Working Group Guidance Team

Chair

Dr Paul Dawkins, Respiratory Physician Counties Manukau DHB

Members

Dr Jonathan Adler, Consultant Palliative Care, Capital and Coast DHB

Dr Denise Aiken, Physician and Clinical Director Medicine Lakes DHB

Dr Scott Babington, Radiation oncologist, Christchurch Hospital

Dr Ben Brockway, Consultant and senior lecturer in respiratory medicine, Dunedin Hospital and Dunedin School of Medicine, University of Otago, Dunedin

Dr John Childs, Radiation oncologist Auckland

Dr Paul Conaglen, Cardiothoracic Specialist Waikato DHB

Dr James Entwisle, Radiologist, Capital and Coast DHB

Dr Greg Frazer, Respiratory and general physician, Christchurch Hospital; clinical senior lecturer, University of Otago, Christchurch

Dr David Hamilton, Radiation oncologist, Capital and Coast DHB

Dianne Keip, Clinical care coordinator, Hawke's Bay DHB

Dr George Laking, Medical Oncologist, Auckland DHB

Professor Ross Lawrenson, Professor of Population Health University of Waikato; Clinical Director Waikato Hospital

Dr Brendan Luey, Consultant medical oncologist, Capital and Coast DHB

Dr Kim McAnulty, Radiologist, Waikato Hospital, Waikato Clinical School, University of Auckland

Dr Felicity Meikle, Thoracic surgical fellow, Dunedin

Dr Aisha Paulous, General Practitioner, South Island

Jo Stafford, Consumer and Māori representative, Auckland

