

LUNG CANCER SURVIVORSHIP BRIDGE PROGRAM TOOLKIT

 **WVU**CancerInstitute™



The Bridge Program is funded through the Bristol-Myers Squibb Foundation

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INTRODUCTION AND OVERVIEW

The *Bridge Program*

As part of Vice-President Joe Biden's Cancer Moonshot Initiative, the Bristol-Myers Squibb Foundation (BMSF) pledged \$25 million to address disparities in cancer care and support. In October 2016, BMSF funded the WVU Cancer Institute (WVUCI) to address the needs of lung cancer survivors and their caregivers in West Virginia and created the *Bridge to Good Living: Thriving Beyond Lung Cancer* Program, also referred to as *the Bridge Program*, one of the first Moonshot initiatives funded.

The overarching goal of the *Bridge Program* is to improve the coordination of care and decrease the consequences of treatment for patients diagnosed with lung cancer.

Purpose of this Toolkit

This toolkit is designed for oncology providers, primary care providers, advanced practice professionals, and/or cancer treatment teams interested in implementing a comprehensive lung cancer survivorship program. This resource includes information about the needs of lung cancer patients following treatment and tools for oncology teams to use in coordinating a multidisciplinary survivorship care program.

What is Survivorship?

It is well-documented that overall cancer survivorship in the United States is growing. As of January 2016 it was estimated that there were 15.5 million cancer survivors in the U.S. The number of cancer survivors is projected to increase by 31%, to almost 20 million by 2026, which represents an increase of more than 4 million survivors in 10 years.^{1, 2}

The National Coalition for Cancer Survivorship (NCCS) defines a survivor as a person diagnosed with cancer “from the time of diagnosis and for the balance of life”.³

Survivorship care focuses on health after treatment and encompasses physical, psychological, and socioeconomic issues.⁴ The Institute of Medicine lays out four essential elements of survivorship care:

1. Surveillance for the recurrence of cancer, new primary cancers, medical and psychosocial late effects;
2. Prevention of recurrent or new cancers and of late effects of treatment;
3. Intervention for consequences of cancer and treatment; and
4. Coordination between oncology specialists and primary care physicians.⁴

Specific to West Virginia, currently 1 in 8 residents is a cancer survivor. Cancer is now considered a chronic disease and the number of people living five years or more after diagnosis is projected to increase by 35% over the next eight years.

The need for survivorship care, assisting patients in transitioning to life beyond cancer, is more important now than ever. Survivorship care plans go beyond a medical document. Survivorship planning not only tells a patient where they have been, it details a patient's treatment history and outlines a plan for future care.

Why Lung Cancer?

Lung cancer is the second most common cancer in both men and women in the United States.⁵ Similarly, in West Virginia lung cancer is the second most common cancer type in both men and women and accounts for 18% of all new cancer cases diagnosed. Annually, 2,039 people are diagnosed with the disease while 1,482 will die from lung cancer. In addition, more West Virginians will die from lung cancer than colorectal, prostate, and breast cancers combined.⁶

Patients who are diagnosed with late stage lung cancer are often referred to supportive or palliative care programs that provide symptom management; psychosocial support and follow up; as well as advanced planning. In contrast, the needs of patients diagnosed at a curable or early stage (stages 1-3) often go unaddressed.

The United States Preventative Services Task Force now recommends low-dose computed

tomography (LDCT) to screen for lung cancer. Current or former smokers, ages 55-80, who have pack-year smoking history of 30 or greater should receive the LDCT annually. In addition, new medications and developing treatment pathways demonstrate great promise for lung cancer patients. These significant strides in early stage diagnosis and treatment of lung cancer will continue to increase the number of early stage lung cancer survivors. This population of early stage lung cancer patients is the focus of this toolkit.

THE IMPORTANCE OF SURVIVORSHIP CARE PLANNING IN LUNG CANCER

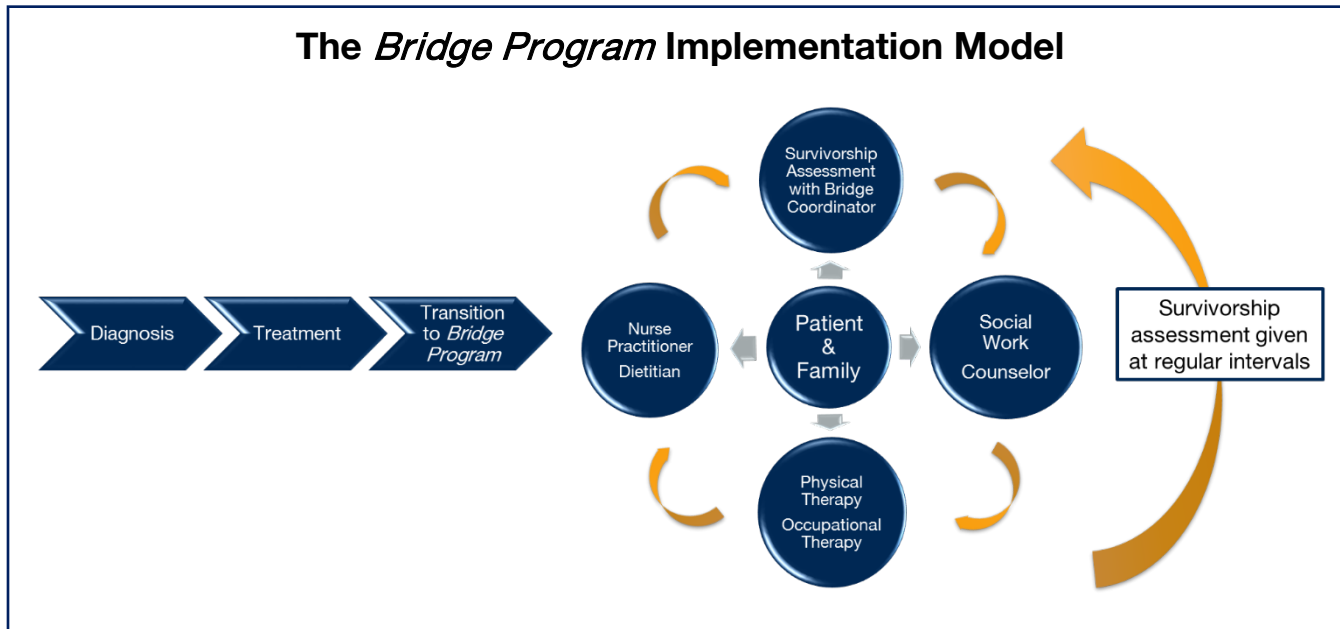
Survivorship care plans were first recommended by the Institute of Medicine in 2006 to help the increasing number of cancer survivors address the challenges often faced after treatment. In 2015, the Commission on Cancer (CoC) added survivorship care plans to its standards for all CoC accredited cancer centers.

With an increase in aging of our population coupled with improvements in cancer care, there are a growing number of cancer survivors. Caring for those cancer survivors requires efficient care models and transitions between health care systems due to the shortage of oncologists and primary care physicians in many areas.

Lung cancer survival rates historically have been low, leading to quality of life efforts focusing on patients with advanced disease. The late and long-term effects of therapeutic modalities also determine quality of life. Often there are gaps in the ability of survivors and providers to adequately address and manage the patient's post-treatment chronic physical and psychosocial effects.

According to the 2010 National Health Interview Survey, poor physical and mental health was reported at a significantly higher rate by cancer survivors than adults without a history of cancer. In a weighted analysis, poor physical health was reported by 24.5% of cancer survivors versus just 10.2% of people without a history of cancer. Cancer survivors reported poor mental health at a rate of 10.1% while people without a history of cancer only reported at 5.9%. ⁷ Based on the literature, it is expected that lung cancer survivors would follow these trends.

CANCER SURVIVORSHIP CARE MODELS: A VARIETY OF APPROACHES



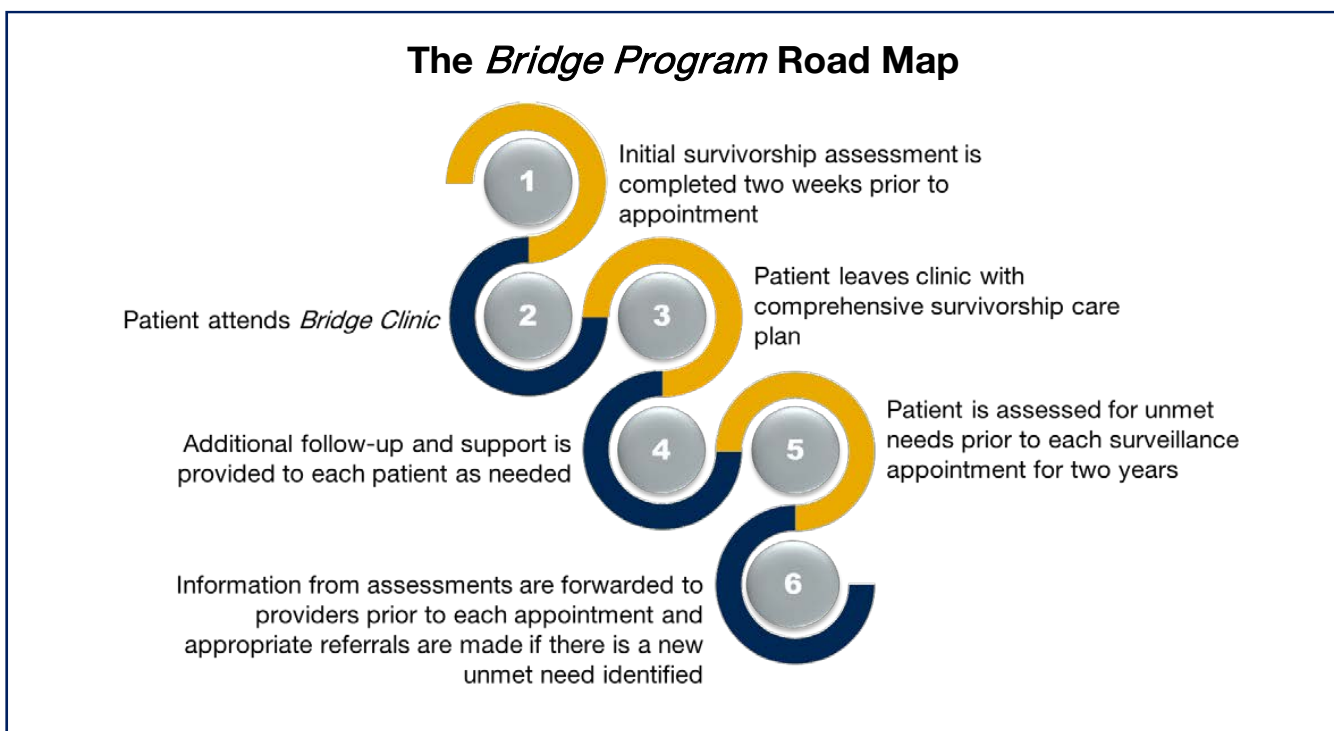
A Multidisciplinary Team Approach

The *Bridge Program* utilizes a multidisciplinary team format, where each patient sees up to six clinical professionals in one appointment. The *Bridge Team* consists of a nurse practitioner, physical therapist, occupational therapist, dietitian, social worker, and mental health professional. The *Bridge Team* also includes a program coordinator who completes a phone assessment with each patient and assists with follow-up. The program coordinator also assists the patient with completing referrals, finding community resources, and completing quarterly assessments.

The Multidisciplinary Team sees the patient individually during a one hour appointment. Each team member has the opportunity to assess the patient in person and then come together to discuss presenting problems. This team-based approach creates an opportunity for collaboration and information sharing that leads to the development of an enhanced survivorship care plan.

The survivorship care plan is individualized to each patient based on the team's recommendations. The program coordinator assists the patient in any follow-up necessary, makes appointments based on referrals, finds resources based on unmet needs, and facilitates communication with the team.

As depicted in the *Bridge Program* Road Map, a patient will begin with an initial survivorship assessment before his/her *Bridge Clinic* visit. At that visit, the patient will leave with a comprehensive survivorship care plan. If the patient has any need for follow-up and support, those referrals and/or support services will be provided at that time. Then the patient continues to be assessed for any unmet needs prior to each surveillance appointment for up to two to five years. The information gathered through the ongoing assessments is shared with the oncology and multidisciplinary team members prior to each oncology follow-up appointment. Appropriate referrals are made if there is a new unmet need identified.



It is important to note:

- While most patients who receive radiation and/or chemotherapy complete follow-up appointments every 3-4 months (depending on the oncologist), most surgery patients only return every six months.
- Once a patient completes a survivorship visit with the *Bridge Program* and receives a survivorship care plan, they do not return for another visit with the *Bridge Program* multi-disciplinary team unless the disease team makes a referral.

Bridge Program Patient Assessment

For *Bridge Program* patients, the late and long-term effects of multiple therapeutic modalities are identified through a survivorship assessment.

Prior to each patient attending the *Bridge Clinic*, the program coordinator completes a 5-10 minute assessment over the phone to determine major areas of concern. The survivorship assessment asks patients to rate common issues for lung cancer survivors on a scale of 0-4 (0 – not at all concerned, 4 – very concerned). See Appendix A for a sample unmet needs assessment.

Below is a complete list of common unmet needs for lung cancer survivors based upon the American Society of Clinical Oncology survivorship care plan for lung cancers and current scientific literature.

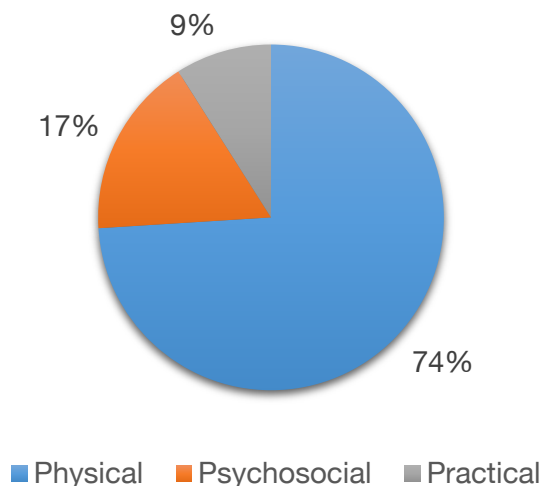
Bridge Program Survivorship Assessment Areas

PSYCHOSOCIAL	PHYSICAL	PRACTICAL
Alcohol Use	Balance & Falling	Financial Issues & Advice
Tobacco Use	Breathing	Insurance
Anxiety/Depression	Exercise & Physical Activity	School or Work Concerns
Emotional & Mental Health	Fatigue	
Fear of Recurrence	Memory & Concentration	
Spiritual Issues & Support	Pain	
Parenting	Neuropathy	
	Physical functioning & Self-Care	
	Preventative Care	
	Sexual Functioning	
	Sleep	
	Weight changes, diet, or difficulty eating	

Identified Needs

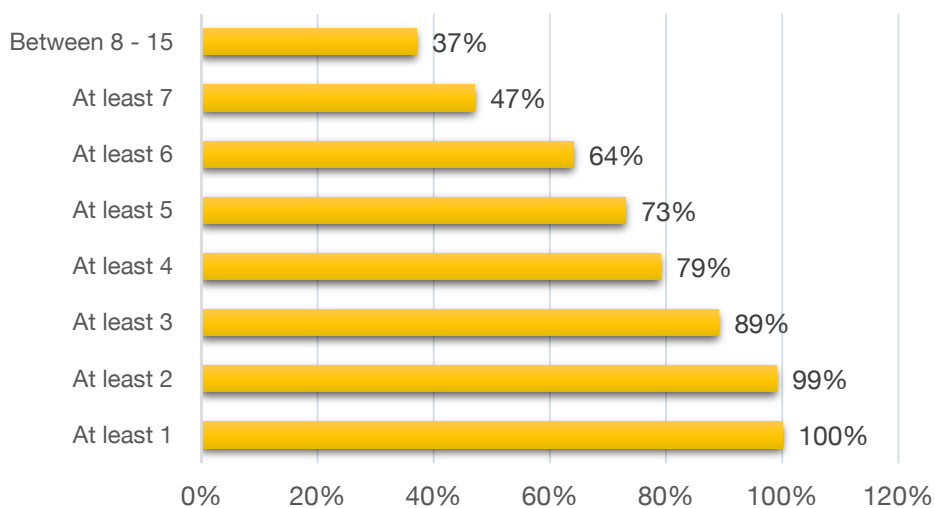
When split into three categories: physical, psychosocial, and practical, *Bridge* patients identified more unmet needs in the physical category than any other. In addition, the number of unmet patient needs ranged from at least one to as many as 15.

Bridge Program Patient Identified Needs by Category



Bridge patients at WVUCI only as of March 2019

Number of Identified Needs per *Bridge Program* Patient



Bridge Program patients at all sites as of March 2019

Considerations for Survivorship Models

In survivorship care planning one size does not fit all. The goal of survivorship care planning is to wrap all of the services available around a patient to ensure they have the best chance at long term survival. While the *Bridge Program* uses a multidisciplinary team approach to lung cancer survivorship, a variety of models may be utilized to provide patients with a comprehensive care plan. Depending on the size of the facility and personnel available, adjustments to the model may be necessary but our team has demonstrated the importance of involving multiple disciplines in the post- treatment assessment.

Although the *Bridge Program* utilizes a multidisciplinary team model when executing the clinic one day a month, it is sometimes difficult for patients to return to the WVU Cancer Institute in Morgantown for additional appointments following treatment. To accommodate these patients, the team tailors the timing of the clinic to coincide with the patient's final treatment appointment. Although the full multidisciplinary team may not be present for these appointments, the patient is assessed, treatment needs are identified, and the team members are consulted when developing the comprehensive care plan.

The nurse practitioner completes the survivorship care plan and reviews the plan thoroughly with the patient prior to the completion of the appointment. The case manager or patient navigator continues to follow the patient, make quarterly contact, and assists with the resolution of unmet needs.

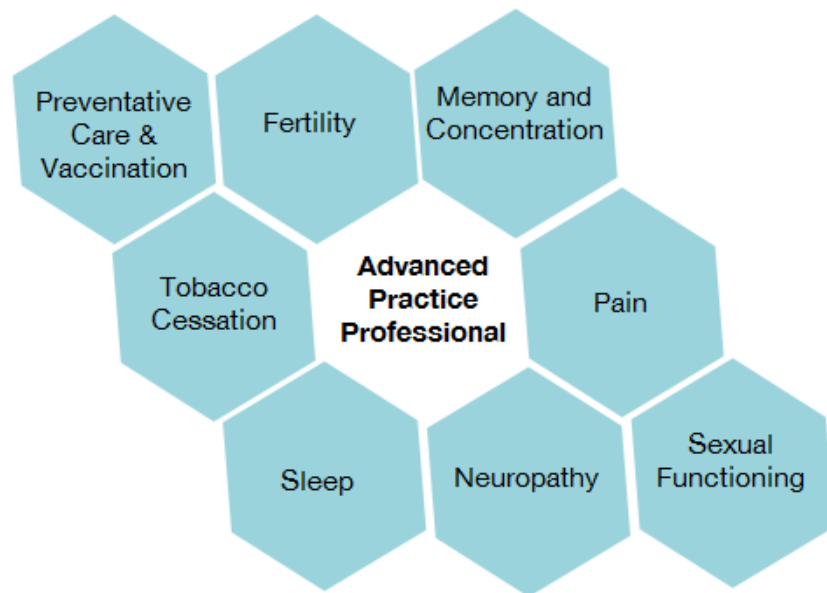
Regardless of a patient or clinic's decision to participation in the full *Bridge Program* or a modified version, the path through the *Bridge Program* Road Map (found on page 10) is essentially the same. Each patient is given the opportunity to discuss his/her concerns after treatment through the survivorship assessment either prior to the multidisciplinary appointment (in the full *Bridge Program*) or at his/her final treatment appointment prior to the development of the survivorship care plan.

A MULTIDISCIPLINARY CARE TEAM: THE ROLE OF SPECIALISTS

The *Bridge Team* consists of a variety of clinical professionals with experience in oncology.

The **advanced practice professional (APP)** provides medical advice about the patient's diagnosis, treatment, late effects of treatment, and creates the survivorship care plan per CoC guidelines. At the end of the appointment, the APP reviews the full survivorship care plan with the patient and answers all questions. In addition to providing medical knowledge necessary, the APP provides the following additional services:

- Completes any referrals recommended by the team,
- Writes prescription(s) for necessary medication(s) or nicotine replacement therapies (NRTs) if the patient is still using tobacco products, and
- Reviews the survivorship care plan according to CoC standards.



The **oncology social worker** is a crucial part of the *Bridge Team* because he or she brings knowledge of resources so frequently sought by patients completing cancer treatment. The social worker can also assist patients in dealing with insurance and financial security questions as well as assisting patients in filing for disability if they are not able to return to work.

In the absence of a mental health professional, the Social Worker addresses concerns about parenting; school and work related issues; anxiety and depression; and emotional and mental health concerns.



The **mental health professional** such as a psychologist, psychiatrist, or counselor serves on the multi-disciplinary team to provide patients with mental health services vital to patients when completing lung cancer treatment. If a mental health professional is not readily available for every clinic, their participation may have to be requested based on the results of the initial survivorship assessment.

At the WVU Cancer Institute the *Bridge Team* requests that a psychologist or psychiatrist is present at appointments when patients report a concern with anxiety or depression.



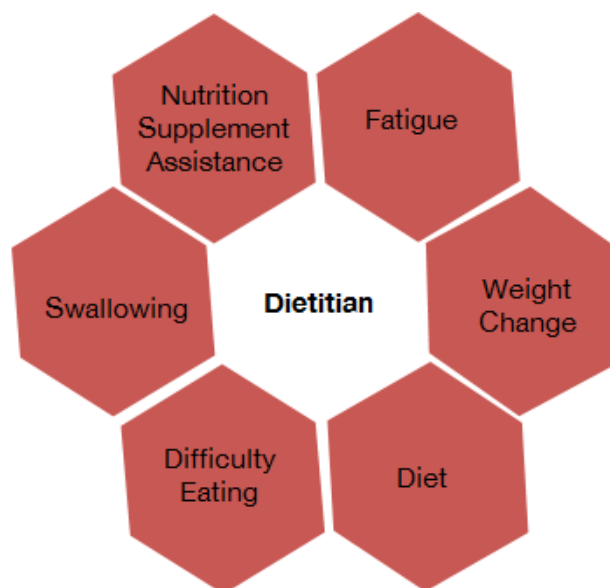
The **physical and occupational therapists** work in tandem to assist patients in not only regaining strength (physical therapy), but also conserving energy so that they can complete vital daily tasks (occupational therapist).

Physical and occupational therapy are the most common suggestions provided to *Bridge Program* patients, whether those activities are completed in a traditional PT/OT setting or provided in the form of exercises performed at home.



More specifically, problems with balance and falling are the most frequently cited areas for concern of lung cancer survivors enrolled in the *Bridge Program*, and PT/OT can improve functioning in these areas.

The **dietitian** typically works with lung cancer patients who receive chemotherapy and/or radiation therapy. Patients most commonly experience difficulty swallowing, weight change, and/or difficulty eating. A dietitian can also provide information for patients on how to obtain dietary supplements at a reduced cost.



SURVIVORSHIP: LANGUAGE MATTERS

As discussed at the beginning of this toolkit, survivorship is a term used to describe cancer patients from the time of diagnosis through the course of their life. We have also discussed that the CoC describes the plans given to cancer patients who have completed treatment as survivorship care plans. Most cancer centers use the term survivorship to describe all cancer patients who have completed treatment. However, our team at the WVU Cancer Institute began to see problems with this term almost from the launch of our program because the use of the word survivor did not resonate with lung cancer patients.

Initially titled *The Bridge to Good Living: Thriving Beyond Lung Cancer* when speaking to clinicians and patients, we frequently abbreviated the title to the *Lung Cancer Survivorship Program*. We learned quickly that both our patients and our oncologists were not comfortable using the word survivor.

As a result, our team labeled our service as the *Bridge Program* instead of a survivorship program. In our communications to oncologists, oncology teams, and our patients, we avoided using the term survivor to describe the program. The *Bridge Program* offered patients a chance to begin addressing the consequences of treatment as well as make lifestyle changes as they bridged back to life beyond treatment.

NEXT STEPS

Review of this toolkit provides a basic overview for what is needed and how to execute a multidisciplinary survivorship program.

In addition to comprehensive care, survivors at the WVUCI also receive a patient handbook that provides additional information about life after lung cancer. A sample introductory letter to the *Bridge Program* and a table of contents for this handbook can be found in the Appendices E and F.

To learn more about lung cancer and survivorship, the WVUCI and *Bridge Program* team recorded podcasts that can be found at <http://wvucancer.org/cancer-prevention-control/podcasts/>.

If you are interested in learning more about the topics presented here or have any questions, contact WVUCI Cancer Prevention and Control at cpc@hsc.wvu.edu or 304-293-2370.

Appendix A: Unmet Needs Assessment

Script: Each of the following areas can be issues for people moving from active cancer treatment to recovery ('survivorship'). Some of these may apply to you and some may not. Please make a mark in the box (*or tell me*) how much each item is a concern for your recovery.

	0 Not a concern at all	1 A little concerning	2 Somewhat concerning	3 Moderately concerning	4 Very concerning
Alcohol use					
Anxiety or depression					
Balance and falling					
Breathing difficulties					
Emotional and mental health/wellbeing					
Exercise/physical activity					
Fatigue					
Fertility					
Financial advice or assistance					
Insurance					
Memory or concentration					
Pain					
Parenting					
Peripheral neuropathy/numbness/tingling					
Physical functioning/getting around/self-care					
Preventative care/vaccinations					
Recurrence/second cancer					
School/work					
Sexual functioning					
Spiritual issues/support					
Sleep					
Stopping smoking/tobacco use					
Weight changes/diet/difficulty eating					

Additional comments:

Appendix B: Survivorship Care Plans

The Bridge Program addresses patient-identified needs through use of an enhanced survivorship care plan. The American Society of Clinical Oncology (ASCO) issued recommendations on treatment and survivorship care plan components and the CoC outlined minimum components required for treatment summaries and care plans. The CoC's minimum requirements for survivorship care plans include the following components.

Treatment Summary Components

- Contact information of the treating institutions and providers.
- Specific diagnosis (e.g. breast cancer) including histologic subtype (e.g. non-small cell lung cancer) when relevant
- Surgery (yes/no). If yes:
 - Surgical procedure with location on the body
 - Date(s) of surgery (year required, month optional, day not required)
- Chemotherapy (yes/no). If yes:
 - Names of systemic therapy agents administered (listing individual names rather than regimens)
 - End date(s) of chemotherapy treatment (year required, month optional, day not required)
- Radiation (yes/no). If yes:
 - Anatomical area treated by radiation
 - End date(s) of radiation treatment (year required, month optional, day not required)
- Ongoing toxicity or side-effects of all treatments received (including those from surgery, systemic therapy, and/or radiation) at the completion of treatment and any information concerning the likely course of recovery from these toxicities.
- For selected cancers, genetic/hereditary risk factor(s) or predisposing conditions and genetic testing results if performed

Care Plan Components

- Oncology treatment team member contact information with location of treatment facility
- Need for ongoing adjuvant therapy for cancer including:
 - Adjuvant therapy name
 - Planned duration
 - Expected side effects
- Schedule of follow-up clinical visits, presented in table format including:
 - Who will provide the follow-up visit
 - How often and where the visits will take place
- Cancer surveillance tests for recurrence, presented in table format including:
 - Who is responsible for ordering/carrying out the test
 - Frequency of testing
 - Where testing will take place
- Cancer screening for early detection of new primary cancers—included only if different from the general population, presented in table format including:
 - Who is responsible for carrying out the screening
 - Frequency of testing
 - Where testing will take place
- Other periodic testing and examinations
 - The ASCO team recommends including a general statement to “continue all standard non-cancer related health care with your primary care provider, with the following exceptions (if there are any).”
- Possible symptoms of cancer recurrence.
 - The ASCO team recommends a general statement, “Any new, unusual and/or persistent symptoms should be brought to the attention of your provider.”
- List of likely or rare but clinically significant late- and/or long-term effects that a survivor may experience based on his or her individual diagnosis and treatment
- List of areas survivors commonly experience issues
- General statement emphasizing the importance of a healthy diet, exercise, smoking cessation, and alcohol use reduction may be included
 - Statements can be tailored to the individual

Appendix C – ASCO Survivorship Care Plan for Small Cell Lung Cancer

General Information		
Patient Name:	Patient DOB:	
Patient phone:	Email:	
Health Care Providers (Including Names, Institution)		
Primary Care Provider:		
Surgeon:		
Radiation Oncologist:		
Medical Oncologist:		
Other Providers:		
Treatment Summary		
Diagnosis		
Cancer Type/Location/Histology Subtype: Small cell lung cancer		Diagnosis Date (year):
Stage: Limited Stage		
Treatment Completed		
Surgery <input type="checkbox"/> Yes <input type="checkbox"/> No		Surgery Date(s) (year):
Surgical procedure/location/findings:		
Radiation <input type="checkbox"/> Yes <input type="checkbox"/> No	Body area treated:	End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other) <input type="checkbox"/> Yes <input type="checkbox"/> No		
Names of Agents Used		End Dates (year)
<input type="checkbox"/> Carboplatin		
<input type="checkbox"/> Cisplatin		
<input type="checkbox"/> Etoposide		
<input type="checkbox"/> Paclitaxel		
<input type="checkbox"/> Vincristine		
<input type="checkbox"/> Other		
Persistent symptoms or side effects at completion of treatment: <input type="checkbox"/> No <input type="checkbox"/> Yes (enter type(s)) :		
Treatment Ongoing		
Need for ongoing (adjuvant) treatment for cancer <input type="checkbox"/> Yes <input type="checkbox"/> No		
Additional treatment name	Planned duration	Possible Side effects

Follow-up Care Plan																	
Schedule of Clinical Visits																	
Coordinating Provider	When/How often																
Cancer Surveillance or other Recommended Tests																	
Coordinating Provider	Test	How Often															
<p>Please continue to see your primary care provider for all general health care recommended for a man/woman your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:</p> <ol style="list-style-type: none"> 1. Anything that represents a brand new symptom; 2. Anything that represents a persistent symptom; 3. Anything you are worried about that might be related to the cancer coming back. 																	
<p>Possible late- and long-term effects that someone with this type of cancer and treatment may experience:</p> <ul style="list-style-type: none"> • Constipation • Fatigue • Hair loss • Hearing loss • Kidney problems • Lung fibrosis or scarring • Memory loss • Nausea • Peripheral neuropathy (numbness/tingling) • Pneumonitis or inflammation of lung tissue • Skin rash • Trouble or painful swallowing 																	
<p>Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.</p> <table border="0"> <tr> <td><input type="checkbox"/> Anxiety or depression</td> <td><input type="checkbox"/> Insurance</td> <td><input type="checkbox"/> Sexual Functioning</td> </tr> <tr> <td><input type="checkbox"/> Emotional and mental health</td> <td><input type="checkbox"/> Memory or concentration loss</td> <td><input type="checkbox"/> Stopping Smoking</td> </tr> <tr> <td><input type="checkbox"/> Fatigue</td> <td><input type="checkbox"/> Parenting</td> <td><input type="checkbox"/> Weight changes</td> </tr> <tr> <td><input type="checkbox"/> Fertility</td> <td><input type="checkbox"/> Physical functioning</td> <td><input type="checkbox"/> Other</td> </tr> <tr> <td><input type="checkbox"/> Financial advice or assistance</td> <td><input type="checkbox"/> School/work</td> <td></td> </tr> </table>			<input type="checkbox"/> Anxiety or depression	<input type="checkbox"/> Insurance	<input type="checkbox"/> Sexual Functioning	<input type="checkbox"/> Emotional and mental health	<input type="checkbox"/> Memory or concentration loss	<input type="checkbox"/> Stopping Smoking	<input type="checkbox"/> Fatigue	<input type="checkbox"/> Parenting	<input type="checkbox"/> Weight changes	<input type="checkbox"/> Fertility	<input type="checkbox"/> Physical functioning	<input type="checkbox"/> Other	<input type="checkbox"/> Financial advice or assistance	<input type="checkbox"/> School/work	
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<input type="checkbox"/> Fertility	<input type="checkbox"/> Physical functioning	<input type="checkbox"/> Other															
<input type="checkbox"/> Financial advice or assistance	<input type="checkbox"/> School/work																
<p>A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:</p> <table border="0"> <tr> <td><input type="checkbox"/> Alcohol use</td> <td><input type="checkbox"/> Physical activity</td> <td><input type="checkbox"/> Other</td> </tr> <tr> <td><input type="checkbox"/> Diet</td> <td><input type="checkbox"/> Sun screen use</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Management of my medications</td> <td><input type="checkbox"/> Tobacco use/cessation</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Management of my other illnesses</td> <td><input type="checkbox"/> Weight management (loss/gain)</td> <td></td> </tr> </table>			<input type="checkbox"/> Alcohol use	<input type="checkbox"/> Physical activity	<input type="checkbox"/> Other	<input type="checkbox"/> Diet	<input type="checkbox"/> Sun screen use		<input type="checkbox"/> Management of my medications	<input type="checkbox"/> Tobacco use/cessation		<input type="checkbox"/> Management of my other illnesses	<input type="checkbox"/> Weight management (loss/gain)				
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<input type="checkbox"/> Management of my other illnesses	<input type="checkbox"/> Weight management (loss/gain)																
<p>Resources you may be interested in:</p> <ul style="list-style-type: none"> • www.cancer.net 																	

<ul style="list-style-type: none"> Other: 	
Other comments:	
Prepared by:	Delivered on:

- This Survivorship Care Plan is a cancer treatment summary and follow-up plan and is provided to you to keep with your health care records and to share with your primary care provider or any of your doctors and nurses.
- This summary is a brief record of major aspects of your cancer treatment not a detailed or comprehensive record of your care. You should review this with your cancer provider.

Appendix D – ASCO Survivorship Care Plan for Non-Small Cell Lung Cancer

General Information		
Patient Name:	Patient DOB:	
Patient phone:	Email:	
Health Care Providers (Including Names, Institution)		
Primary Care Provider:		
Surgeon:		
Radiation Oncologist:		
Medical Oncologist:		
Other Providers:		
Treatment Summary		
Diagnosis		
Cancer Type/Location/Histology Subtype: Non-Small Cell Lung Cancer		Diagnosis Date (year):
Stage: <input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> Not applicable		
Treatment Completed		
Surgery <input type="checkbox"/> Yes <input type="checkbox"/> No		Surgery Date(s) (year):
Surgical procedure/location/findings:		
Radiation <input type="checkbox"/> Yes <input type="checkbox"/> No	Body area treated:	End Date (year):
Systemic Therapy (chemotherapy, hormonal therapy, other) <input type="checkbox"/> Yes <input type="checkbox"/> No		
Names of Agents Used		End Dates (year)
<input type="checkbox"/> Carboplatin		
<input type="checkbox"/> Cisplatin		
<input type="checkbox"/> Gemcitabine		
<input type="checkbox"/> Paclitaxel/Docetaxel		
<input type="checkbox"/> Pemetrexed		
<input type="checkbox"/> Vinorelbine		
<input type="checkbox"/> Other		
Persistent symptoms or side effects at completion of treatment: <input type="checkbox"/> No <input type="checkbox"/> Yes (enter type(s)) :		
Treatment Ongoing		
Need for ongoing (adjuvant) treatment for cancer <input type="checkbox"/> Yes <input type="checkbox"/> No		
Additional treatment name	Planned duration	Possible Side effects
Follow-up Care Plan		

Schedule of Clinical Visits																	
Coordinating Provider	When/How often																
Cancer Surveillance or Other Recommended Tests																	
Coordinating Provider	Test	How Often															
<p>Please continue to see your primary care provider for all general health care recommended for a (man) (woman) your age, including cancer screening tests. Any symptoms should be brought to the attention of your provider:</p> <ol style="list-style-type: none"> 4. Anything that represents a brand new symptom; 5. Anything that represents a persistent symptom; 6. Anything you are worried about that might be related to the cancer coming back. 																	
<p>Possible late- and long-term effects that someone with this type of cancer and treatment may experience:</p> <ul style="list-style-type: none"> • Constipation • Esophageal stricture • Hearing loss • Kidney problems • Peripheral neuropathy or numbness and tingling • Pneumonitis or inflammation of the lung (3-6 months after treatment) • Pulmonary fibrosis or scarring • Trouble with or painful swallowing 																	
<p>Cancer survivors may experience issues with the areas listed below. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them.</p> <table border="0"> <tr> <td><input type="checkbox"/> Anxiety or depression</td> <td><input type="checkbox"/> Insurance</td> <td><input type="checkbox"/> Sexual Functioning</td> </tr> <tr> <td><input type="checkbox"/> Emotional and mental health</td> <td><input type="checkbox"/> Memory or concentration loss</td> <td><input type="checkbox"/> Stopping Smoking</td> </tr> <tr> <td><input type="checkbox"/> Fatigue</td> <td><input type="checkbox"/> Parenting</td> <td><input type="checkbox"/> Weight changes</td> </tr> <tr> <td><input type="checkbox"/> Fertility</td> <td><input type="checkbox"/> Physical functioning</td> <td><input type="checkbox"/> Other</td> </tr> <tr> <td><input type="checkbox"/> Financial advice or assistance</td> <td><input type="checkbox"/> School/work</td> <td></td> </tr> </table>			<input type="checkbox"/> Anxiety or depression	<input type="checkbox"/> Insurance	<input type="checkbox"/> Sexual Functioning	<input type="checkbox"/> Emotional and mental health	<input type="checkbox"/> Memory or concentration loss	<input type="checkbox"/> Stopping Smoking	<input type="checkbox"/> Fatigue	<input type="checkbox"/> Parenting	<input type="checkbox"/> Weight changes	<input type="checkbox"/> Fertility	<input type="checkbox"/> Physical functioning	<input type="checkbox"/> Other	<input type="checkbox"/> Financial advice or assistance	<input type="checkbox"/> School/work	
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<p>A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:</p> <table border="0"> <tr> <td><input type="checkbox"/> Alcohol use</td> <td><input type="checkbox"/> Physical activity</td> <td><input type="checkbox"/> Other</td> </tr> <tr> <td><input type="checkbox"/> Diet</td> <td><input type="checkbox"/> Sun screen use</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Management of my medications</td> <td><input type="checkbox"/> Tobacco use/cessation</td> <td></td> </tr> <tr> <td><input type="checkbox"/> Management of my other illnesses</td> <td><input type="checkbox"/> Weight management (loss/gain)</td> <td></td> </tr> </table>			<input type="checkbox"/> Alcohol use	<input type="checkbox"/> Physical activity	<input type="checkbox"/> Other	<input type="checkbox"/> Diet	<input type="checkbox"/> Sun screen use		<input type="checkbox"/> Management of my medications	<input type="checkbox"/> Tobacco use/cessation		<input type="checkbox"/> Management of my other illnesses	<input type="checkbox"/> Weight management (loss/gain)				
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<p>Resources you may be interested in:</p> <ul style="list-style-type: none"> • www.cancer.net • Other: 																	

Other comments:	
Prepared by:	Delivered on:

- This Survivorship Care Plan is a cancer treatment summary and follow-up plan and is provided to you to keep with your health care records and to share with your primary care provider or any of your doctors and nurses.
- This summary is a brief record of major aspects of your cancer treatment not a detailed or comprehensive record of your care. You should review this with your cancer provider.

Appendix E – Introductory Letter for Patient Handbook

Welcome,

The staff of the *Bridge to Good Living: Thriving Beyond Lung Cancer Program* welcomes you to this new phase of cancer care. You have completed active treatment and may be wondering, "What comes next?" Well for all cancer patients, especially lung cancer patients, it is extremely important to keep your follow-up appointments so that your medical team can monitor you for recurrence and side effects. In addition to your physician and regular care team, you will now have the Survivorship Team at your service.

Cancer survivorship is defined as the time from diagnosis until the end of one's life, but we know that it is hard for people who are engaged in active treatment to even think about such a thing. Now that you have completed active treatment, whether that was surgery, radiation, chemotherapy, or immunotherapy; you can begin to consider just what this means for you. It is likely that you will still have some needs and that is where we come in. Our program is set up to help you and your family members:

- identify unmet needs and ongoing concerns,
- assist with access to care, and
- provide resources and support as you and your family adapt to life after lung cancer

We encourage you to talk freely with the staff, build relationships, and ask questions. We may not always know the answers, but we will find the information that you need. The material in this Patient Handbook is provided to answer some of your questions and be a place where you can keep all of your medical information. At the end of your first appointment, a Treatment Summary and Survivorship Plan developed just for you will be added to this notebook. Please take some time to read the information and share it with your loved ones.

We look forward to working with you on your cancer survivorship journey and invite you to join with us in this partnership.

Sincerely,

Cancer Center Director

Appendix F – Patient Handbook Table of Contents

Survivorship care plan	This section remains empty until the end of the patient's appointment; after review with the nurse practitioner the plan is placed in this tab.
Purpose of the program	Sample introductory letter found in Appendix E.
Team members	Photos, name, and title of each team member is found in this tab followed by business cards for each.
Living with lung cancer	Coping mechanisms are shared in this section.
Stopping tobacco use	Helpful information on tobacco cessation for patients who continue to experience nicotine dependence.
Nutrition	Nutrition information for cancer survivors.
Physical activity	Physical activities and questions for patients to ask their physicians.
Daily living skills	Understanding the role that an occupational therapist can play in making daily living activities possible after treatment.
Social services	Explains the importance of a social worker and mental health professional post-treatment.
Resources	Local resources focusing on tobacco cessation and lung cancer support groups.
Cancer Survivorship	ASCO Answers Cancer Survivorship – trusted information about life after treatment from the American Society of Clinical Oncology.

References

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