

# Appendix 4: Full Clinical Practice Tool

## Improving Quality of Life While Living with Cancer

**General Information to Assess Needs and the Related Options for  
Improving Quality of Life While Living with Cancer**

Provided to: \_\_\_\_\_

Date: \_\_\_\_\_

By: \_\_\_\_\_

Dear reader,

Advanced cancer is a disease that can no longer be healed by an operation or taking medicine, or it is a cancer that has spread to other organs. When living with advanced cancer, different and changing needs emerge. These needs are different from person to person.

Oncologists, oncological nurses, and other professionals (such as psychologists, chaplains, physical therapists, dieticians, etc.) are committed to the work of helping people who experience challenges because of their illness. They are there to support you so that you can have the best possible quality of life despite your disease.

This information and the systematic needs assessment was developed in order to help you have more targeted communication with your oncologists, oncology nurses, and other professionals. The assessment helps to ensure that the whole array of topics is covered. These topics are ones which may be important to you as a cancer patient or may be relevant to your family.

**“This information was developed to help you communicate with your oncologists, oncology nurses, and other professionals”**

In this pamphlet there is information on the following topics:

- Symptoms caused by cancer or cancer treatment
- Illness and illness progression
- Decision making about cancer therapies
- Support at home
- Support by and support for your family
- Spiritual needs
- Preparing for the end of life

Your needs can be documented on the assessment form (Page ...) and then measures can be taken with your treatment team to address your needs.

### **Recommended Reading**

For further information, we recommend *A Guide for Patients with Advanced Cancer* from the European Society for Medical Oncology.

## Symptoms caused by cancer or cancer treatment

Cancer and cancer treatment can cause difficult symptoms such as pain, fatigue, nausea, loss of appetite, difficulty breathing, depression and/or anxiety. Recording the severity of your symptoms allows professionals to offer the best possible treatment to relieve your symptoms. Recording symptom severity may also empower you to find ways you can help yourself to cope with symptoms.

## Illness and prognosis

Cancer comes in many forms. There are over 300 different types of cancer. If you understand exactly which kind of cancer you have and which parts of your body are affected, then you can better understand the problems you experience and how you can best be helped. Think about what you understand about your sickness and how it will progress. Perhaps you have questions about this. Your questions could relate to how serious your situation is and how your illness will unfold in the future.

## Decision-making regarding your cancer treatment (tolerability, goals, effectiveness)

There is more than one right way to treat advanced cancer. You need adequate information in order to decide between different treatment options, such as chemotherapy, immunotherapy, or radiation therapy. It is your oncologist's job to explain each option to you, including the advantages and risks of each option. This helps you to decide on a treatment plan that is right for you.

Each person makes decisions differently. Some patients want to gather all relevant information and options and then make a decision, either alone or in cooperation with the oncologist. Other patients prefer for the oncologist to decide which treatment is best for them. No matter how you make your decisions, it is important that you let your oncologist know about how you want him or her to be involved in your decision making.

## Support at home and creating a care network

It takes a lot of energy and effort for cancer patients and their family to meet the demands of everyday life. Activities that used to be performed without difficulty can become challenging after a hospitalization or over the course of the disease. It is important to know who can help, for example, who will help you if you have a (physical) complaint or if your condition worsens.

## Family support

It is common that patients have difficulty remembering what their doctor/oncology healthcare provider said, and this is especially true for difficult, emotionally-charged conversations. It can be helpful to have a family member or friend present for discussions during medical appointments.

The situation is also often very stressful for the family. For this reason, your medical team is also concerned about the needs and wellbeing of your family. Family members can benefit from the help of therapists, social workers, palliative care specialists, psychiatrists, psychologists, psycho-oncologists and/or chaplains.

### Preparation for the End of Life

You may have already given thought to the care you would like to receive at the end of your life. Perhaps you have already taken actions in this regard.

- You have completed or are considering a living will to document your wishes in case you are incapacitated.
- You have signed or are considering a power of attorney regarding financial and legal matters.
- You have a plan or intend to discuss with your doctor your wishes regarding CPR or other life-saving measures in the event of cardiovascular failure.
- You have decided or intend to discuss with your doctor your wishes about what will happen with your body after your death (autopsy, organ donation).
- Perhaps you have unfinished business (legacy, reconciliation) you want to address.

### Spirituality

Spirituality means something different for every person. For some people, it is connected with religious faith. For others spirituality is a feeling of connection, a sense of purpose or even values that have nothing to do with religion. Psychological support and spiritual ministry can help patients and their families to deal with the challenges posed by advanced cancer by addressing these very meaningful dimensions of life.

# Assessment of Symptom Levels and Questions About the Need for Support

Patient Sticker

Date: \_\_\_\_\_

Assessment	Palliative Interventions	Completed	Delegated	Completed	Delegated	Completed	Delegated
<p><b>1. First, estimate the intensity of the symptom</b> in the last 24 hours on a scale from 0 to 10 (0= none to 10= worst possible).</p> <p><b>2. Then consider whether you have a need for support</b> from an oncological professional.</p>	<p><i>Legend for Abbreviations:</i></p> <p>O= Oncologist                      PO= Psycho-oncologist            SPO= Supp./Pall. Oncologist    D= Dietician            PT= Physical Therapy            ON= Oncology Nurse              Z= Other</p>						
<p><b>Pain</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Fatigue (Lack of Energy)</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Nausea</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Loss of Appetite</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Anxiety (Inner Unrest/Nervousness)</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Depression (Feelings of Sadness)</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Breathlessness</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Drowsiness (Dizziness/ Sleepiness)</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
<p><b>Other Symptoms</b></p> <p>0 1 2 3 4 5 6 7 8 9 10</p> <p><b>Need for Support?</b></p> <p><input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>	Notes:						
Notes	<i>Further Measures to be Taken</i>						

## Needs, Demands, and Supports while Living with Cancer

<b>Assessment</b>	<b>Palliative Interventions</b>	<b>Completed</b>	<b>Delegated</b>	<b>Completed</b>	<b>Delegated</b>	<b>Completed</b>	<b>Delegated</b>
<p><b>1. First, estimate the intensity of the symptom</b> in the last 24 hours on a scale from 0 to 10 (0= none to 10= worst possible).</p> <p><b>2. Then consider whether you have a need for support</b> from an oncological professional.</p>	<p><i>Legend for Abbreviations:</i></p> <p><i>O= Oncologist                      PO= Psycho-oncologist</i>  <i>SPO= Supp./Pall. Oncologist    D= Dietician</i>  <i>ON= Oncology Nurse              PT= Physical Therapy</i>  <i>Z= Other</i></p>						
<p><b>Illness and Illness Progression</b> Are you dealing with questions about your illness and its progression?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
<p><b>Decision Making about Cancer Therapy</b> Are you dealing with questions about how you will tolerate treatment, the goals of treatment, or the effect of treatment?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
<p><b>Support at home and Creating a Care Network</b> Are you dealing with questions about your support at home, for example when you experience (physical) symptoms or if your condition worsens at home?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
<p><b>Support for Your Family</b> Is your family currently struggling with the situation and needs professional support or advice?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
<p><b>Preparing for the End of Life</b> Have you given thought to how you want to be treated at the end of your life and are you dealing with questions such as living will, power of attorney, will, legacy, reconciliation, etc.?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
<p><b>Spirituality</b> Are you dealing with questions of spirituality, such as belief, religion, reasons for living, hope, hopelessness, etc.?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
<p><b>Other Issues:</b> _____ Which other issues are you dealing with?</p> <p style="text-align: center;"><b>0 1 2 3 4 5 6 7 8 9 10</b></p>	Notes:						
<p><b>Need for Support?</b>  <input type="checkbox"/> no    <input type="checkbox"/> no problem in this area    <input type="checkbox"/> already receive support  <input type="checkbox"/> yes    <input type="checkbox"/> low    <input type="checkbox"/> medium    <input type="checkbox"/> high</p>							
Notes	<i>Further Measures to be Taken</i>						

## Notes

Date	