

SENS – a prompt sheet with important themes for patients with serious illness

What is this prompt sheet for?

This prompt sheet aims at providing an overview over several problems but also resources in increasingly difficult, burdening and sometimes apparently desperate situations. It helps to coordinate care to not "drown" in the diversity and magnitude of tasks and burdens. To make the best out of life in difficult situations, to plan ahead and therefore to maintain a certain control – that is the aim of this sheet.

This is a prompt sheet – that means that it can and should be worked on step by step. Ideally - if desired and experienced as helpful – it can be done together with your partner and family or friends.

Based on the experience of many people who needed to orientate themselves in similar situations, we defined the following four main topics: Symptom management, End-of-life decisions and Expectations, Network, Support of the carers. This shortens to the abbreviation SENS – in Latin this means 'sense'. We hope that this prompt sheet will also make sense to you. The Palliative Care Team works with the same structure. This way we find easily a common language.

Discuss the single areas also with professionals from the medical, nursing, psychology, spiritual care and social work – whoever you trust. This document can and should serve as preparation for so-called Round Tables or family conferences. These are planning discussions between you, your family and the professionals about "what if..." or "how can I continue...". Possibly, you want to define an advance directive based on the discussion of the themes.

Don't hesitate – ask us and discuss your concerns and questions with us. We would like to be seen as your partner.

Your Palliative Care - Team at the Inselspital



UCI UNIVERSITY CANCER CENTER INSELSPITAL ZENTRUM FÜR PALLIATIVE CARE

Symptom management

Which problems/ themes/ symptoms cause most of my suffering at this moment? Which ones scare me for the future? In relation to which of the symptoms below do I feel anxiety?

But also: which positive experiences do I have in regard of coping with these problems/ themes/ symptoms/ challenges (= so called resources)?

Physical	Psychological	<u>Spiritual</u>	Socio-cultural	
e.g. pain	e.g. limitations in think- ing / memory	e.g. faith/ religion	e.g. own role (family/ profession)	
nausea/vomiting dyspnea / shortness of breath	confusion grief, anger	search for meaning	traditions/ rituals relationship to others relationship to profes- sionals	
fatigue / weakness loss of appetite	anxiety depression	suffering relationship to some- thing bigger – more meaningful other:		
digestion	sleep impairment		financial concerns legal concerns	
other:	changes in the body im- age/ feeling of shame		other:	
	loneliness other:			

My most important resources / sources of energy are:

End-of-life decisions and Expectations

Looking back - have I so far taken important decisions myself (alone, with ...)? Or - did I mainly relay on the advice of others? Or - did others usually decide for me?

What is particularly important for me? What would I like to urgently experience or finish in the upcoming time? Which goals would I like to achieve (with which medical treatment)?

Which questions concerning my disease are still unanswered? What (and how much) more would I like to know? What are my expectations in terms of medical treatment?

In regard to dying: what needs to be finished: what would I like to plan (e.g. in relation to an advance care planning)? What is my attitude concerning life-prolonging measures, resuscitation in case of a cardiac arrest, about the question what should be done with my body after I died (autopsy, organ donation)? Do I have certain wishes, expectations what should be done with me in times in which I cannot decide for myself anymore (incl. care, rituals, funeral)?

Is there any unfinished business or things that I urgently need or want to tackle or organize?

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Do I need specific advice or support (e.g. for financial matters)?

Network

If my health status does not improve largely, where would I like to be the most / what is my favorite place of living? How are the local circumstances (e.g. stairs, access to the bathroom / toilette)?

Who can support me / my family when my strength is deteriorating? Whom of my personal surrounding (family, friends) could I consult or get involved? Which professionals (e.g. social services, mobile palliative services, general practitioner, volunteers) are available?

If there is a complication / an emergency: what do I do / what can we do concretely? What can I / people in my private surrounding do ourselves, whom do we call in that case? Which professionals (e.g. mobile palliative services, general practitioner) can come to my home – also during the night? Do we need the ambulance ("144") and what for? With all of that in place: how does the "chain of rescue" look like?

Which alternatives for further care (e.g. caregiving institution) do I have? Should I plan for an alternative in case my preferred place of care (e.g. at home) is no more an option?

Support for the family/ friends

Who of my most important / closest family or friends would probably need support themselves – whom am I worried about the most? Who is already there as a support – professionals, family, friends? If I die – who is there to help also after my death?

Other questions, remarks:

Version

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