INSELSPITAL
UNIVERSITÄTSSPITAL BERN
HÔPITAL UNIVERSITAIRE DE BERNE

UNIVERSITÄRES ZENTRUM
FÜR PALLIATIVE CARE

SENS - MANUAL FOR PROFESSIONALS

BASICS

Instructions for using the SENS structure

for Assessment, Treatment Planning and Evaluation in Palliative Care

TABLE OF CONTENTS

1 Origin 3
2 Theoretical background 3
3 Definition 4
4 Time of application 4
5 Application in practice 5
6 Initial assessment procedure (basic palliative care assessment) 6
  6.1 WHAT: Analysis of stress and resource areas according to SENS. 6
    6.1.1 Introduction 6
    6.1.2 **S** ymptoms / effects of the disease 6
    6.1.3 **E** xpectations and decision making 7
    6.1.4 **N** ework/ Organization 7
    6.1.5 **S** upport for the relatives / caregivers 8
    6.1.6 Further considerations 8
  6.2 HOW 9
    6.2.1 The procedure: palliative assessment 9
    6.2.2 The anamnesis 9
    6.2.3 The big picture 9
  6.3 Practical implementation 10
7 Initial assessment from the perspective of those affected 10
Attachments 11

1 ORIGIN

The SENS[1] structure was developed on the basis of the thematic evaluation of 500 consultation reports of the palliative consultation service at the Cantonal Hospital St.Gallen in the context of the development of the quality standard "Palliative Care". The aim was to find a common thematic structure for patients, relatives and professionals, and thus an equally guiding and meaningful mapping of the main concerns in advanced diseases. These topics should create a common language, rather than focusing on medical and nursing terminology. Problems and concerns should be addressed, as well as one's own resources and sources of energy to better cope with the coming phase of life.

2 THEORETICAL BACKGROUND

The SENS structure is conceptually based on the following background:

- The bio-psycho-social medicine model of George Engels[2], which emphasizes the importance and also the healing power of relationships/interactions in a broad network from the cell, to partnership/family, to spirituality/the universe;
- The concept of salutogenesis by Aaron Antonovsky[3]: it emphasizes the importance of the so-called "sense of coherence" in order to not feel helpless and at the mercy of others despite very difficult life situations. This is based on three areas: comprehensibility, manageability (e.g. help for self-help), and finally meaningfulness, which can, but does not have to, follow from this.

The domains of the SENS structure correspond to the World Health Organization (WHO) definitions of palliative care, the content of the Gold Standard Framework (GSF), and the main themes of the recommendations of the NCCN (2016), the US National Comprehensive Cancer Network (see Fig.1).

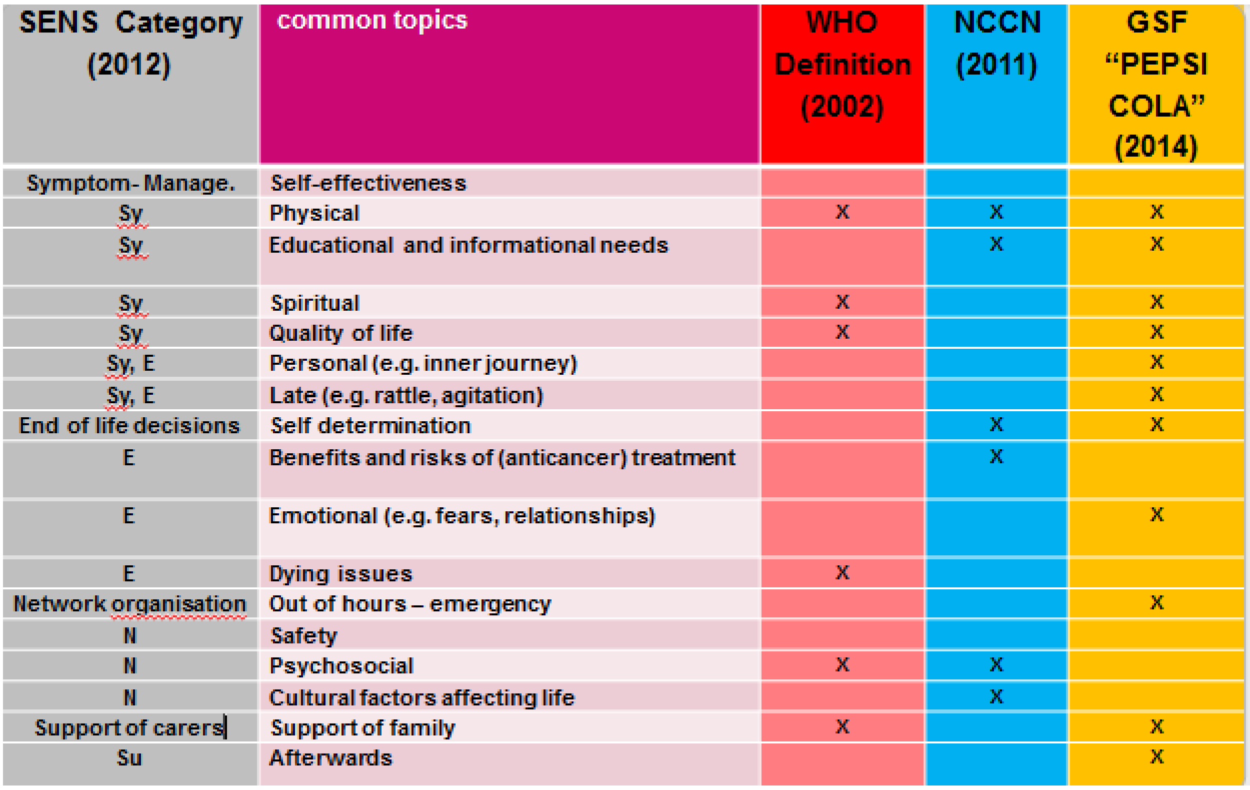
The content of the SENS structure was qualitatively checked for validity and completeness as part of the national research project "End of Life" (NFP67) in the so-called "SENS Trial".

---

[1] The acronym "**SENS"** stands for symptoms, decision-making, network, support of relatives

[2] Engels G (1980). The clinical application of the biopsychosocial model. 137(5), 535-544. The American Journal of Psychiatry. http://dx.doi.org/10.1176/ajp.137.5.535

[3] Antonovsky A (1997). Salutogenesis. On the demystification of health. Dgvt, Tübingen.



SENS Category (2012)	common topics	WHO Definition (2002)	NCCN (2011)	GSF "PEPSI COLA" (2014)
Symptom-Manage.	Self-effectiveness			
Sy	Physical	x	x	x
Sy	Educational and informational needs		x	x
Sy	Spiritual	x		x
Sy	Quality of life	x		x
Sy, E	Personal (e.g. inner journey)			x
Sy, E	Late (e.g. rattle, agitation)			x
End of life decisions	Self determination		x	x
E	Benefits and risks of (anticancer) treatment		x	
E	Emotional (e.g. fears, relationships)			x
E	Dying issues	x		
Network organisation	Out of hours – emergency			x
N	Safety			
N	Psychosocial	x	x	
N	Cultural factors affecting life		x	
Support of carers	Support of family	x		x
Su	Afterwards			x

Fig.1: Topic overview SENS, WHO definition, NCCN and GSF.

3 DEFINITION

SENS is a practice-oriented thematic procedure structure for assessment, treatment planning and evaluation of chronically progressive and/or potentially life-threatening diseases. SENS focuses on the problems but also on the resources of those affected in the everyday areas of life and strengthens self-efficiency in dealing with the new life situation through a participatory approach. SENS sees itself as complementary to the medical-diagnostic and therapeutic approach and aims to map the contents of palliative care in a structure that is understandable, simple and quickly learnable for all involved.

4 TIME OF APPLICATION

The "trigger" for the application of the SENS structure is not a temporal but a **content-related** definition of palliative care: The "when" is less relevant than the "what". In the case of some diseases, the application of the SENS structure already makes sense at the time of the initial diagnosis. The idea is to carry out a problem- and resource-related assessment and corresponding planning for various areas of life in parallel with diagnosis-specific diagnostics and therapy.

Since SENS mainly concerns the planning of everyday life in the context of the (new or progressive) medical diagnosis or relapse diagnosis, the person affected and his/her environment can and must become active themselves here, with the result of a treatment plan jointly supported by all those involved. The basic motto is: plan for the difficult, hope for the best, or also: everything that comes better is good. The active participation of those affected in the process (shared decision making, shared responsibility) is essential from the outset in the sense of salutogenesis.

A central advantage of this parallel and substantively complementary approach is particularly evident in the case of far advanced suffering, the actual main competence of palliative care: do diagnosis-specific measures become too toxic in view of the deteriorated general condition, or is the expected balance between benefit and harm is unfavorable, a well-prepared treatment plan for the SENS areas is in place. "We can do nothing more for you" thus gives way to the statement: "now the side effects of the diagnosis-specific (e.g. tumor-specific) therapy very probably predominate, the focus should now be on the SENS plan".

Triggering questions to the affected person can be: "are you worried about what the diagnosis X now means for you and your life"? "do you ask yourself what they could do now themselves (in order not to feel overwhelmed by the new reality)"?

Triggering questions for the professionals can be: "Do you have the impression that the person affected is very stressed by the new situation? "Would it be helpful if the person affected were to deal intensively and in a structured way with the effects of the new diagnosis/recurrence/progression diagnosis on his/her own areas of life? "Would it be useful if the affected person created or updated a living will"? "Would you be surprised if the affected person were to pass away in the next 6 to 12 months?" (so-called 'surprise' question[4]).

5 APPLICATION IN PRACTICE

The following clinical situations and action steps have proven useful for applying the SENS structure in palliative care:

1. Initial assessment (basic palliative assessment) by professionals as a basis for treatment planning, possibly followed by targeted use of specific assessment tools (e.g. for cognition, pain, etc.).
2. Initial self-assessment from the perspective of the person concerned ("prompt sheet" or SENS worksheet) as the basis for treatment/procedure planning and, if necessary, the basis for advance planning within the framework of a living will/advance care planning (ACP).
3. Definition of treatment/care plan with medical and problem/resource-specific components incl. emergency planning
4. Composition of an interprofessional treatment team according to the required competencies (outpatient and/or inpatient)

---

[4] E.g. Moroni M et al. (2014). The 'surprise' question in advanced cancer patients: a prospective study among general practitioners. Palliative Medicine. Vol. 28(7) 959- 964. SAGE. DOI: 10.1177/026921631452627

5. Evaluation of an existing treatment plan/team in terms of prioritization, composition, loading or overloading, and in finding new solutions.
6. Documentation (also: round table, diagnosis list "complex palliative situation") and coordination in the treatment network
7. Structuring case reflections and in teaching/learning including patient education in palliative care.

6 INITIAL ASSESSMENT PROCEDURE (BASIC PALLIATIVE CARE ASSESSMENT)

6.1 WHAT: ANALYSIS OF STRESS AND RESOURCE AREAS ACCORDING TO SENS.

6.1.1 INTRODUCTION

The goal is to create a "map" of current stress and resource areas (see Appendix 1):

a) What is the cognitive and emotional situation (i.e. to what extent is assessment possible?).
b) Is anamnesis possible? If yes, with patient alone, with relatives?
c) What is the probability of survival (prognostic factors, "good feeling").
d) Which needs/goals are in the foreground?
e) What expectations are formulated for the professional staff/treatment and care?
f) "What causes most of your suffering?" (R. Twycross[5]): Recording of suffering/stressors > problems > diagnoses (see SENS). Which worries are in the foreground (prioritization)?
g) What does the affected person himself see as the most important resources/ helps/ sources of energy?

6.1.2 S YMPTOMS / EFFECTS OF THE DISEASE

At the beginning of the assessment, the current performance status (using Karnofsky/ ECOG) is documented. Other instruments such as ESAS, DOS, pain assessment using, for example, NRS or VAS, etc. can be used for specific assessments.

On the one hand, the focus in the assessment of symptoms is on the question **"What is currently causing the most concern?"** and on the other hand, the resources are always queried in parallel "What is doing you good, what makes the symptoms better?".

---

[5] Twycross RG (2003). Introducing palliative care. 4th ed. Radcliffe Medical Press Ltd.

Physical symptoms	Exhaustion/fatigue, pain, nausea, shortness of breath, appetite, nutrition/weight, digestion, constipation, general well-being, others (pruritus; edema), skin symptoms/mucous membranes incl. dry mouth, neurological symptoms incl. spasms
Psychological symptoms	Cognition/ confusion/ hallucinations Memory, depression/ demoralization, stress/ anxiety, sleep disturbance, mood incl. desire to die, defense/ coping, distress.
Social stressors/ effects of the disease	on relationships (partnership/ family) incl. intimacy/ sexuality on profession / previous activities on finances
Most important personal resources/ sources of energy	E.g. family, hobbies, pets, spirituality

6.1.3 EXPECTATIONS AND DECISION MAKING

Personal history	Central question: 'What do we need to know about you in order to treat you well'? Previous life content (family, career), medical history, values, quality of life.
Spiritual/ cultural needs	Belonging to faith or spiritual community Dealing with questions of meaning
Planning / expectations / patient goals	Main goals and wishes: 'What should/can be achieved by the upcoming treatment?' Realistic? Measurand (function)? Current judgment Most important representative for medical decisions a) Relatives b) Specialist c) Who has the lead/ who is the main contact person?
Medical and nursing decisions	Knowledge and understanding of the current medical situation, if applicable, what gaps? Continue or stop current diagnosis-specific therapy (e.g. chemotherapy, dialysis, etc.) Pre-existing policy decisions (CPR, intub., intensive care, AB, transfusions, hospital admissions, emergency plan)Nursing needs or wishes, if any.
Individual planning for dying and death (Usually not at initial assessment, as relationship building is necessary first).	"Unfinished business" - last wishes Wishes regarding rituals, place of death, burial Autopsy Will

6.1.4 NEWORK/ ORGANIZATION

Living conditions	Current housing situation, alternatives considered Resources Occupation/ AUF/ IV applied for
Private network	Relatives - system description (possibly socio-ecological genogram); most important person(s) of trust; possibly weekly plan for support by relatives/ friends
Network of professionals	Family doctor (home visits?), involved services (Spitex, mobile palliative service), specialists; most important medical officer, social work, psychological support, pastoral care -> who has the lead and who takes over in which situation? Emergency button/wristwatch, rescue chain?

6.1.5 SUPPORT FOR THE RELATIVES / CAREGIVERS

Worries about relatives	Important: record what is bothering the patient!
Resilience and Relief options for relatives/friends	Existing or necessary: - Care support - General care (e.g. night watch, housekeeping) - Psychological support
Financial stressors for family members	Support from employer for temporary leave from work? Financial bottlenecks in the future? Health care proxy?
Other stressors related to loved ones	

6.1.6 FURTHER CONSIDERATIONS

a) Who do you need for which topic?
b) What information does the affected person and his/her environment need?
c) Completion of diagnosis-specific data and temporal prognosis; telephone call/consultation with primary care physician/specialist, etc., if necessary.
d) Initial prescription of diagnostics and drug therapy, prescription of complementary measures

6.2 HOW

The goal is not to create an additional burden with the capture.

6.2.1 THE PROCEDURE: PALLIATIVE ASSESSMENT

The palliative assessment procedure is determined by the condition of the individual(s).

i. Patient - anamnesis directly with the patient
ii. Patients - history indirectly via relatives and/or involved specialist(s)
iii. Environment - anamnesis via relatives and/or involved specialist(s), in particular family doctor

Important: we need to account for how much of the remaining life we take with history (i.e., how much of the standard information we can capture through other sources, e.g., primary care physician).

6.2.2 THE ANAMNESIS

In most cases, we take a so-called "fractionated anamnesis", i.e., we briefly discuss the most important aspects initially and then explore the other details in coordination with other professions. Particularly in the case of highly distressing symptoms such as shortness of breath or pain, about 5 minutes of anamnesis must suffice initially (see Chapter 6.1.6, questions a - d). In most cases, really important points (e.g., main factors for suffering) are not mentioned until a relationship of trust has been established.

The anamnesis must cover the so-called "unit of care". The overall view should provide clarification with regard to the patient, his relatives and his other caregivers/trusted persons. Direct contact with the general practitioner or other pre-treatment providers such as Spitex or other medical specialists is always recommended.

6.2.3 THE BIG PICTURE

The art of the anamnesis interview is that we ask as few points as possible twice or even three times. For this reason, an internal "passing of the baton" must take place during the anamnesis of palliative patients, initial assessment always jointly by nursing and medicine on the basis of the SENS structure (incl. who does what when). The process resembles a "circumstantial process" according to Sherlock Holmes: different pieces of the puzzle are put together and coordinated. The overall picture emerges only in the interprofessional team.

6.3 PRACTICAL IMPLEMENTATION

Before taking the medical history, the assistant physician contacts the nursing staff: Exchange what is already known from the patient and what still needs to be asked (to avoid duplication).

The initial assessment is carried out by the assistant physician and (reference) nurse together (at least main goals and problems based on the SENS assessment. This is followed by a brief discussion between doctor and nurse based on the SENS assessment document together with the senior physician. The initial treatment plan is then drawn up.

This includes:

a) Involvement of other specialists (e.g. specialists, physiotherapy, psychology, social work, etc.)
b) Definition of the basic decisions (CPR, disposition)
c) Initial prescriptions incl. reserve medication for emergency situation
d) Missing information, e.g. consultation with family doctor

7 INITIAL ASSESSMENT FROM THE PERSPECTIVE OF THOSE AFFECTED

In accordance with the SENS structure, a worksheet was developed for those affected (patient, relatives), which is intended to serve as a so-called "prompt sheet" , as a preparatory script for the participatory development of the treatment plan and possibly as a basis for discussing the contents of an advance directive. The SENS worksheet can also provide valuable services in the partnership-based preparation of a round table to ensure that the individual perspective of those affected is given sufficient weight in the development of the treatment plan (cf. Annex 2).

ATTACHMENTS

Appendix 1: SENS assessment structure for initial assessment/ basic palliative assessment

Appendix 2: SENS worksheet for affected persons

Appendix 1:

SENS - Assessment overview for professionals

Name:

Date:

Expectations of treatment/care	
Symptoms / effects of the disease	
Current performance status	Karnofsky: ECOG:
Physical symptoms: 'What currently worries you the most?'	
• Exhaustion/ Fatigue • Shortness of breath • Pain • Appetite, diet/weight • Nausea • Stool / urine • Edema • Skin symptoms / mucous membranes incl. dry mouth • Neurological symptoms incl. spasms • Other:	*Problem description & helpful/ medications*
Psychological symptoms/ stressors	
• Cognition/ confusion/ hallucinations • Depression/ Demoralization • Stress/ Anxiety • Sleep disorder • Other:	
Social stressors/social impact of the disease.	
• Profession/ previous activity • Relationships (partnership/ family) incl. intimacy/ sexuality • Finance	
Most important personal resources/ sources of energy	*E.g. family, hobbies, pets, spirituality*

Decision making and expectations	
Personal history: 'what do we need to know about you to treat you well'?	
- Previous medical history, values, quality of life Spiritual / cultural needs - Belonging to faith or spiritual community - Dealing with questions of meaning	
Planning/ expectations/ patient goals: 'What should/ can be achieved?'	
Main goals and wishes: 'What do you want to achieve through the upcoming treatment?'	
- Current judgment - Most important confidant for medical decisions a) Relative/ representative b) Specialist c) Who has the lead? Main contact person?	
Medical & nursing decisions - Current medical situation/ planned therapies - pre-existing policy decisions (CPR, intub., intensive care, AB, transfusions, hospital admissions, emergency plan)	
Individual planning for dying and death: - "Unfinished Business" - Desired rituals - desired place of death - Wishes regarding funeral	

Network organization	
Living conditions - Current housing situation, alternatives considered - Resources - Occupation/ AUF/ IV applied for	
Private network - Family, friends, neighbors - Availability 24/7?	
Professional network and availability 24/7 - HÄ (home visits?), Spitex, mobile palliative service, volunteers - Emergency button - Rescue chain? - Psychological support / pastoral care...	
Support for relatives/caregivers	
Resilience and Relief options for relatives/friends - Care - Care (e.g. night watch) - Psychological support Financial stressors for family members	*Important: record what is bothering the patient!*

Appendix 2: SENS Worksheet ("Prompt Sheet")

SENS -

a worksheet for important topics in serious illnesses

What is the purpose of this worksheet?

The aim of this worksheet is to create an overview of various problems but also strengths in an increasingly difficult, stressful and sometimes almost hopeless situation. It serves to coordinate planning and thus ultimately not to "drown" in the multitude of tasks and burdens. To make the best of a difficult life situation, to plan ahead and to keep a certain control - that is the goal.

This is a worksheet, which means that it can and should be worked on step by step. Ideally also together with the partner and family or friends, if this is desired and felt to be helpful.

The division into the four main areas of symptom management, decision making, network and support follows the experiences of many people who had to orient themselves in a similar situation - and the abbreviation then results in SENS - from Latin *meaning*. We hope this worksheet makes sense to you as well. We as a palliative team work with the same topic structure. This makes it easier for you and us to find a common language together.

You are also welcome to discuss the individual areas with your medical, nursing, psychological, pastoral care and social work specialists - in other words, with whom you trust. The document can and should also serve as preparation for so-called roundtable discussions. These are planning discussions between you, your relatives and the specialists on the question of "how to proceed". You may also wish to draw up an advance directive on the basis of these topics.

Ask us too - discuss your concerns with us. We see ourselves as your partners.

Your Palliative Care Team at the Inselspital

Symptom Management

What problems/issues/symptoms are I most concerned about at present or for the future? In relation to which of the items listed below do I feel fear?

But also: what good experiences of my own have I already had in coping with these topics/ problems/ challenges/ symptoms (= so-called resources)?

Physical	**Psychic**	**Spiritual**	**Socio-cultural**
e.g. pain Nausea/vomiting Shortness of breath Fatigue/weakness Loss of appetite Digestion Other:	e.g. limitations in thinking/ memory Confusion Grief, anger Fear Depression Sleep disorder Body image change/ shame Feeling of loneliness Other:	e.g. faith/ religion Question of meaning Hope Suffering Relationship with something greater Other:	e.g. own role (family/job) Traditions/ Rituals Relationship with other fellow human beings Relationship with professionals Financial worries Legal concerns Other:

My main resources/ sources of energy:

Decision making

How have I made important decisions in life so far (alone, with......................)? Or have I mainly relied on the advice of others or let them decide?

What is particularly important to me? What would I like to experience/do urgently in the coming time? What goals do I want to achieve (with the medical measures)?

What questions about my disease have not yet been answered? What (and how much) do I still want to know?

When it comes to dying, what still needs to be taken care of: what do I want to specify in advance (e.g., within the framework of a living will)? What is my position on life-prolonging measures, resuscitation in the event of circulatory arrest, the question of what should happen to my body if I am no longer alive (autopsy, organ donation)? Do I have certain wishes/ideas about what should be done with me when I can no longer decide for myself (incl. care, rituals, burial)?

Are there "unfinished business or things" that I really want to tackle or take care of?

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

Network

If my state of health no longer improves significantly: Where would I prefer to be/ stay? What are the local conditions (e.g. stairs, access to bathroom/ WC etc.)?

Who can support me/my relatives when my strength decreases? Which people from my environment (family, friends) could I involve? Which specialists (e.g. social services, pastoral care, bridge service, Spitex, family doctor, volunteers, etc.) are available?

If a complication/emergency should arise: what do I/we do in concrete terms? What can I/we do in the private environment at the beginning, whom do we call then? Which specialists (e.g. Spitex, family doctor, mobile palliative service) can also come at night? Do we need the Sanpol ("144")? What does our "rescue chain" look like?

What alternatives for further care (e.g. nursing institution) do I have to consider and already plan concretely in advance if care at the place of my choice (e.g. at home) is no longer possible?

Support

Who of my most important/dearest relatives is most likely to need support themselves, who am I particularly worried about? Who are there already as supporters? Professionals? Family/friends? If I pass away, who can help after my death?

Further questions/ comments: