

# GUIDE FOR HEALTHCARE PROFESSIONALS



## HOW TO SUPPORT AND COMMUNICATE WITH INFORMAL CAREGIVERS OF PERSONS WITH CANCER



**ABOUT PSWG**

Since 2007, the ECL Patient Support Working Group (PSWG) connects experts in cancer care who work together to raise awareness and share knowledge in order to improve the quality of cancer care in Europe. PSWG develops best practice guides and provides trainings in areas of patient support, such as access to insurance and financial services, return to work, caregiver support, sexuality and relationship issues, cancer rehabilitation, and palliative care. PSWG members further seek to empower the patient voice in national and European policy-making.

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## FOREWORD

Communication still remains a challenge, despite countless research and publications. Interaction between patients, their families and healthcare professionals is complex. On the one hand, healthcare professionals juggle work protocols, procedures and deal with time constraints while speaking to the patient and their caregivers. On the other hand, patients and caregivers experience stress and come with a lot of concerns. While most guides primarily focus on patients and their needs, the ECL Patient Support Working Group (PSWG) wishes to stress the urgency to address the concerns of their loved ones (i.e., informal caregivers), whose participation in health decision-making is often underrated. It is estimated there are currently more than 100 million caregivers in Europe, however, this number is likely underestimated given the unclear definition and (self-)recognition of informal caregivers.

The PSWG strongly believes that high quality care in oncology should take into account concerns and needs of caregivers, in order to guarantee a sustainable and effective care for patients at the hospital, as well as at home. This guide provides useful principles for healthcare professionals that can improve their support and care for both the patients and their caregivers.

*Alrik Meesen, Chair of the ECL Patient Support Working Group*

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## GUIDE FOR HEALTHCARE PROFESSIONALS

### HOW TO SUPPORT AND COMMUNICATE WITH INFORMAL CAREGIVERS OF PERSONS WITH CANCER

#### THE INFORMAL CAREGIVER: INVISIBLE BUT INDISPENSABLE

Cancer is not a disease that only affects patient's health and well-being, but also that of the family, friends and others who are part of the close network of the patient. This document concerns family members, friends and other people who have a significant non-professional or unpaid relationship with a person with cancer for whom they care. The terms 'family caregivers' and 'informal carers' are used interchangeably with 'carers' in some of the literature. Hereafter, we refer to this group as 'caregivers'.

Caregivers provide more than half the care (in hours) needed by patients with cancer, although the formal healthcare system rarely prepares them for that role. On the contrary, caregivers remain invisible to the healthcare system, are seldom identified as care partners, and are not recognised for the enormous burden of care they shoulder. Nevertheless, healthcare professionals often have high implicit/unarticulated expectations about caregivers' role in providing care at home. Providing such care can be complex and technical, and it requires intellectual and cognitive sophistication and physical endurance. Family members often assume the caregiving role with little or no preparation, and without considering whether they have enough knowledge, resources, or skills. Caregiving has a substantial impact on caregivers' physical and mental well-being, and can negatively influence patients' and caregivers' health outcomes (Northouse, Williams, Given, & McCorkle, 2012; Given, Given, & Sherwood, 2012; Payne, z.d.; Girgis, Lambert, Johnson, Waller, & Currow, 2012; Kom op tegen Kanker, 2015).

Therefore, high quality care in oncology should also take into account concerns and needs of caregivers, in order to guarantee a sustainable and effective care for the person with cancer in the hospital, as well as at home. Caregivers can have beneficial impact on the patient's recovery and clinical outcomes, including reduced postoperative complications resulting from early identification of problems, better management and early detection of adverse events, and increased adherence to oral medication (Northouse, Williams, Given, & McCorkle, 2012).

This document formulates some principles and guidelines that may be useful for healthcare professionals to improve their support and care for patients and their caregivers.

## DIFFERENT ROLES

Supporting caregivers is not always evident, because they occupy an ambiguous role: (i) they may be both providers and receivers of services; and (ii) many caregivers do not define themselves as caregivers, because caring for a family member may be seen as a natural element of a family relationship. Caregiving can potentially give satisfaction and be an expression of altruism, duty and family obligation. Moreover, caregivers may not see their contribution as 'care', because it is often equated with purely physical tasks such as lifting, personal care and help with mobility. Nonetheless, caregiving also encompasses many other tasks such as emotional support, administrative work, helping with medication, arranging transport to the hospital, household tasks and cooking, accompanying the patient to consultations and hospital visits, and managing professional home care. Consequently, caregivers often underestimate their own effort in supporting and helping the person with cancer and neglect their own needs and issues related to caregiving.

For healthcare professionals, it is important to distinguish between the different roles caregivers can play, and take them into account when communicating with and supporting caregivers. These are:

1. the role of a **care partner** who takes up (informal) care tasks and gives support to the person with cancer at home as well as during the hospital journey;
2. the role of a **first-hand source of information** on the patient's everyday health status, experiences and behaviour;
3. the role of a **person in need for care and support** himself due to the cancer diagnosis and the uptake of the caregiving role; and
4. the role of a **relative or a friend** who is emotionally close to the person with cancer.

Hence, facilitating these roles, i.e. cooperating with caregivers, consulting them, supporting them, and facilitating their relationship with the patient will improve the quality of life of both the caregiver and the person with cancer (ActiZ & EIZ, 2007).

## PARTICIPATION IN THE CARE TRAJECTORY

It is recommended that healthcare professionals:

- i. ask patients to **identify their most important support persons** and obtain their consent to involve them in the care trajectory. Discuss the patient's preferences for the involvement of caregivers in medical and care planning discussions, and note this in the medical record and care plan;
- ii. inform patients and caregivers from the very start that care also **includes support for caregivers** and addressing their needs;
- iii. **confirm with caregivers** that they understand the patient has nominated them for this role, explain typical tasks and responsibilities, confirm they are willing to accept this responsibility, and note this in the medical record. Discuss any concerns that caregivers may have in accepting this role (including possible conflicts with other family members);
- iv. understand that a participatory approach is also important for psychological reasons, as it gives **recognition to the caregiver** and may influence the perceived care burden;
- v. **plan consultations** beforehand if relevant aspects (e.g. diagnosis, further inquiries and tests, treatment options, side-effects and consequences of treatment for daily life, dismissal after treatment, etc.) will be addressed, so the primary caregivers know what will happen and are able to participate in these consultations;
- vi. encourage **caregivers to be present** at outpatient consultations and if necessary adapt hours of these consultations in order to facilitate participation by caregivers with paid jobs. At inpatient services, a meeting with the patient and his caregivers should be planned outside the visiting hours, in case caregivers cannot be available during visiting hours;
- vii. communicate with the patient and caregivers, and provide direct and **clear information** in a language they understand - verbally, in writing, or via multimedia;
- viii. always address the perspective of both the patient and caregivers, when issues of treatment and care are discussed;
- ix. **stimulate shared decision-making** by patients and their caregivers when options about treatment and care are discussed, in order to provide treatment and care that is tailored to the needs of the

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patient and their living context. Note that the patient's opinion is decisive and that caregivers are only included in this decision-making process after the patient has given a consent;

- x. designate one healthcare professional (nurse, social worker, etc.) as a **key point of contact** and support during treatment for the patient and the caregiver, so they know who to address with their questions, concerns and issues (face-to-face, by telephone, mail, etc.), and to rely on during the whole care trajectory.

## PREPARING FOR CARE AT HOME

Furthermore, in order to carry out care tasks at home, it is crucial that caregivers:

- I. are explicitly **asked beforehand** about their willingness, capacities and material/financial means to take up care;
- II. are adequately **informed and prepared** to take up care through tailored information and education, including the training of skills in physical care (e.g. medication, wound care, stoma care, etc.), and skills to communicate with and give psychosocial support to the person with cancer;
- III. are fully informed about the **range of professional and other services**, as well as patient groups that are available for support to the person with cancer;
- IV. with paid work are adequately informed about available **allowances, leave, flexible working arrangements** and other benefits, and how they can get access to them;
- V. participate, at the end of the care trajectory, in an interdisciplinary meeting with concerned healthcare professionals **to plan the home transfer** of the patient from the hospital, and thereby ensure a seamless continuation of care at home;
- VI. who have difficulties themselves to seek and provide professional care at home, arrange **care planning and coordination** to be carried out by a concerned healthcare professional;
- VII. also get **help with administrative tasks** (e.g. forms to request allowances, benefits, leave, etc.), as this may be a great relief for caregivers who already feel burdened.

## ADDRESSING THE NEEDS OF THE CAREGIVER

Most caregivers are partners or other close relatives of the person with cancer. They share with the latter emotions of fear, distress, hope, anger, insecurity etc. Moreover, they run the risk of becoming physically and/or psychologically overburdened while carrying out their caregiving tasks. This may have a heavy impact on their own physical and psychological health and quality of life (e.g. ill-health, burn-out, depression, etc.), as well as on the quality of care and support to the person with cancer. Many caregivers may feel reluctant and even guilty to express their own needs and issues they experience, as a result of their caregiving duties. Hence, a real discussion about caregivers' own needs is often neglected and postponed until the moment the care burden becomes untenable. Furthermore, caregivers may experience problems with reconciling their professional duties with their caregiving and family roles, and may sometimes experience social isolation, especially when they decide to stay at home for caregiving.

Therefore, healthcare professionals should pay attention to the needs of caregivers in a more proactive way by:

- i. **regularly taking caregivers aside** to ask about their experiences when caring for the person with cancer. Northouse, Katapodi, Schafenacker, & Weiss (2012) suggested four questions that could be built into a patient assessment or that could be used separately to assess caregiver emotional distress (see Table 1). The questions centre on whether caregivers:
  - a. have the tools to provide optimal care
  - b. are able to deal with multiple responsibilities
  - c. engage in self-care to maintain their health
  - d. are able to keep their spirits up as they deal with the stress associated with caregiving.

There are many questions that could be used for an assessment of caregiver needs, but these key questions should be included in any assessment;

Table 1

**T-A-S-K Questions to Assess for Caregiver Distress**

- a. **Tools?** Do you have what you need (the tools) to provide the best care possible (to the cancer patient)? (e.g. knowledge, time, finances, outside support)
- b. **Able to juggle?** Are you able to juggle your caregiving responsibilities with your other day-to-day responsibilities?
- c. **Self-care?** Are you taking care of yourself? (e.g. taking breaks from caregiving, following healthy lifestyle habits, keeping own healthcare appointments)
- d. **Keeping spirits up?** Are you keeping your spirits up? (e.g. assess for sadness or depression)

(Northouse, Katapodi, Schafenacker, &amp; Weiss, 2012)

- ii. **planning a talk with caregivers alone** in the care trajectory (when a relationship of trust is established between one of the healthcare professionals and the caregiver). A separate talk with caregivers is the safest way for them to express their experiences and needs, and conduct a needs assessment. This should include psychological and physical health, social, spiritual, cultural, financial, and practical elements. Expressed needs and appropriate interventions should be included in the medical record and care plan for the patient;
- iii. providing basic **psychosocial support** to caregivers who have difficulties coping with the situation, and refer (if necessary) to more specialised care professionals. The focus of advice and support provided to caregivers should be based on their choice, and should emphasise strategies to optimise their own well-being;
- iv. emphasising the necessity to guard their own physical and psychosocial limits, and promote/educate **strategies of self-care** among caregivers;
- v. giving full information on the available (regional) **supply of out-of-hours and night support, helplines, professional respite care and peer support activities**, in order to (temporarily) relieve the caregiver burden.

## IN THE PALLIATIVE AND END-OF-LIFE PHASE

Guidelines have been published specifically for caregivers in the palliative and end-of life phase, as well as with respect to bereavement support. See - amongst others - Hudson e.a. (2012) who recommend to:

- I. discuss **advanced care planning** with the patient and family covering any implications relating to the legal responsibilities of caregivers;
- II. convene, whenever possible, a **family meeting**/case conference, including the patient if practicable;
- III. conduct a **needs assessment** with the caregivers. This should include psychological and physical health, social, spiritual, cultural, financial, and practical elements. Once the caregivers' needs are assessed, develop a plan of action with involvement of the caregivers. Initiate the appropriate interventions as pertinent;
- IV. determine the current state of and **risk for poor psychological health and/or prolonged grief**, and plan relevant interventions, based on discussion with the caregivers;
- V. ensure, when death appears imminent, that caregivers are aware, and **assess preparedness for death**;
- VI. contact the caregivers to **offer condolences** and respond to queries, as soon as practicable after the patient's death, by a member of the interdisciplinary team. If death occurred at home, assess the need for a home visit;
- VII. contact caregivers and other family members (as appropriate) **to assess needs at three to six weeks post-death**, and adapt bereavement care plan accordingly;
- VIII. conduct a **follow-up assessment** of caregivers and other family members (if appropriate) six months post-death.

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