A network diagram consisting of numerous small metal pins arranged on a white surface. The pins are interconnected by thin, colored strings (red, green, black, and purple) forming a complex web of connections. The strings are stretched between the pins, creating a series of interconnected triangles and polygons. The overall structure is a dense, interconnected network.

CARTOGRAPHY

OF FACTORS INFLUENCING
FAMILY MEMBERS' / CARERS'
EXPERIENCES OF LOSS

A tool to develop targeted actions

USER GUIDE

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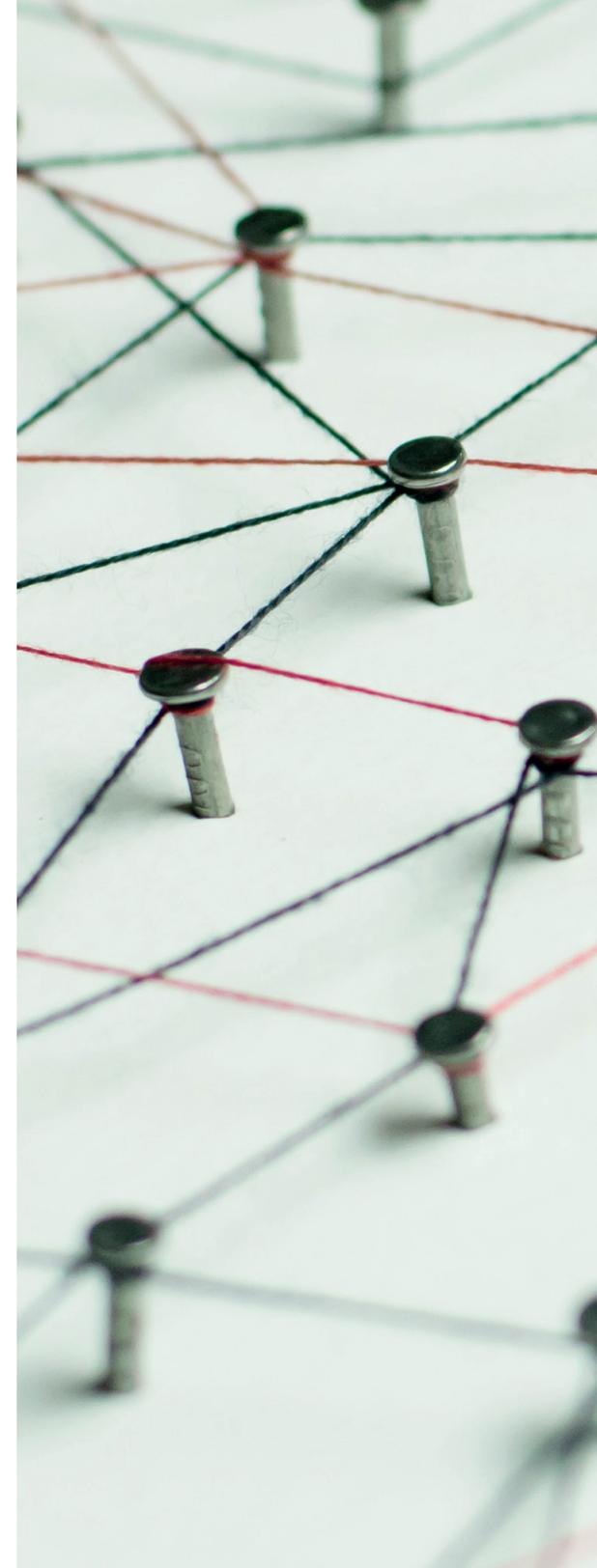
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For blank cartography templates, see pages 16, 17, 18, 38 and 39.

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1

Introduction

This guide presents the cartography of factors influencing family members'/carers' experiences of loss and explains how the tool should be used. It is intended for practitioners providing psychosocial support to individuals living with advanced illness and their family members. These practitioners include psychologists, social workers and social work technicians.

The cartography is a tool that can be used to identify individuals likely to encounter challenges during bereavement. It also identifies *resources* in their environment, which you can use in order to provide support.

The guide is divided in two sections:

1 DEVELOPMENT OF THE TOOL AND RECOMMENDED USE

1. Background
2. Objectives of the cartography tool
3. Description of the cartography tool
4. Recommended use of the cartography tool
5. Two examples of completed cartographies

2 THE CARTOGRAPHY TOOL

1. Five blank cartography templates
2. A factor assessment handbook
3. Contact information for key resource persons
4. Planned follow-up

2

Background

a. Why a cartography tool?

The loss of a person and the ensuing grieving process are unique emotional experiences.

Family members/carers¹ are often very involved in end-of-life care. While the experience of caring can be fulfilling, it also comes with many challenges. Caregivers' journeys are often complex and stressful, and their experiences are influenced by a variety of factors.

The death of a person is often accompanied by secondary losses, which can add to the intensity of the grief. These can include losing a sense of purpose once the person has died, having to move to a smaller home, and having fewer financial resources.

While most grieving individuals cope with the help of their family and friends, and do not require additional support, others may find the process more challenging.

Currently, the health and social services system and its partners do not have sufficient resources to provide follow-up support to all grieving individuals.

¹ The terms "family member/carer" are used to refer to any person who has a supportive relationship with the individual living with advanced illness.



It is therefore up to psychosocial practitioners to identify family members/carers who appear to be at a greater risk of experiencing difficulties following a death. To date, this identification has been based on practitioners' observations and experience. While there are advantages to this intuitive approach, it has its drawbacks, as it does not systematically identify those who may need more intensive follow-up. It could also result in services being offered to individuals who do not really need them.

In order to facilitate and ensure the systematic identification of family members/carers who may need added psychosocial support following a death, this cartography tool identifies a set of factors that could constitute *resources*² or *barriers*³ for bereaved individuals.

b. Development of the cartography tool

This cartography tool is the result of the combined expertise of several teams of researchers and practitioners in the fields of caregiving, bereavement and end-of-life care. The initial factors were identified through interviews with parents of seriously ill children and a literature review (Van Pevenage et al., 2013). The original version of the tool was adapted to an adult context using an interdisciplinary co-construction approach, combining a scientific literature review and the clinical knowledge of palliative care experts (Savoie-Zajc & Descamps-Bednarz, 2007). This final version of the tool was described in an article published in the *Journal of Social Work in End-of-Life & Palliative Care* (Van Pevenage et al., 2019).

2 Aspects of the family member's/carer's situation that could become *resources* to be mobilized during the bereavement period.

3 Aspects of the family member's/carer's situation that could become *barriers* during the bereavement period.



3

Objectives

The cartography tool has four main objectives:

1

Structure the observation of family members/carers in order to identify those who may need more intensive follow-up

2

Adopt more systematic practices to identify these family members/carers

3

Support decision-making around the implementation of an intervention plan

4

Target resources that can be used to develop the intervention plan

4

Cartography factors

The cartography tool (see page 16) is divided into 9 categories of factors that can affect family members'/carers' experiences of loss.

- The family member/carer (e.g., age, gender, personality, mental and physical health)
- The individual living with advanced illness (e.g., age, type and length of illness or incapacity)
- The circumstances of the death (e.g., announcement, anticipated death, sudden death)
- The relationship with the individual living with advanced illness (e.g., nature, duration)
- The family (e.g., family cohesion, intrafamilial communication)
- The family member's/carer's social network (e.g., social life, religious or spiritual groups)
- The family member's/carer's professional and financial situation (e.g., job, work schedule)
- The health and social services environment (e.g., symptom management, quality of information)
- Complicated grief (e.g., death of a child, violent death)



Within these categories, several factors are presented to help you assess the family member's/carer's situation. With the exception of the complicated grief category (see the next page), these factors should be considered neutral.



This means that each factor is potentially either a *resource* or *barrier* for the family member/carer, depending on the situation. Your judgement of the situation will allow you to determine whether a factor is a *resource* or *barrier*.



Why is each factor considered neutral?

1

Every person and situation are unique. A given factor may be a *resource* for one person and more of a *barrier* for another

For example:

Family cohesion can be a *resource* when it is flexible, since it can be adapted to various situations. However, it can also be a *barrier*, for example, in cases of complicated family blending. Having a job can be a *resource* if it allows the family member/carer to find fulfilment in a different environment. However, a job can also be experienced as a burden; in this case, it is a *barrier*.

2

In the scientific literature, factors are rarely seen unambiguously and unanimously as either *resources* or *barriers*.

For example:

Some studies show that the older the bereaved person is, the more resilient they are to death, since they have already had several grieving experiences. However, other studies report that the accumulation of deaths and losses can make the grieving experiences of older adults particularly difficult.





Complicated grief factors

▶ IMPORTANT

In some situations, grief can become complicated. Without elaborating on the diagnostic criteria for assessing pathological grief, certain factors merit particular attention on your part, as they are likely to make the grieving process more complex. These include:

- The death of a child
- A violent or brutal death
- A sudden or prolonged death
- Repeated losses and separations
- Current or past mental health issues
- Social isolation
- Suicide
- Enmeshed relationships

▶ **When one of these factors is identified in a family member/carer, it may not signify a complicated grieving process, but it is strongly recommended that you talk with a member of your team to assess the situation and determine the type of support to be offered.** ◀

5

Recommended use of the cartography tool

a. For whom?

The cartography tool was created for practitioners providing psychosocial support to individuals living with advanced illness and their families/carers—in other words, psychologists, social workers and social work technicians.

The tool can be completed individually or as a team.

b. When to use the tool?

It can take time to identify *resources* and *barriers* for family members/carers and to implement services. It is therefore recommended to use the cartography tool as early as possible in the trajectory of care provided to the individual with advanced illness and his or her family members/carers (pre-death use). However, the tool can also be used at the start of bereavement follow-up (post-death use).



IMPORTANT

You should avoid completing or updating the cartography tool immediately after the death of the person with advanced illness. In the days following the death, grieving individuals may have additional support, but this support tends to diminish afterwards (Hanus, 2006).

c. How to use the cartography tool?

Considering the variety of settings in which practitioners work, there are two options. The first is strongly recommended, but the second may be useful if you have limited means (e.g., time constraints, reduced staff).

Option 1: Conduct a comprehensive assessment and complete the cartography tool in a systematic manner

Individually or as a team, use a colour-coding system to highlight the factors in the cartography tool considered to be *resources* (e.g., green) and *barriers* (e.g., pink). If you cannot decide, leave the factor as is (neutral).

Ideally, the cartography tool should be “coloured” gradually as your knowledge about the family member/carer and their situation evolves. However, you can complete the cartography tool in a single session, if necessary. In this case, it is recommended you complete it as a team in order to obtain diverse clinical perspectives.

The cartography tool comes with a handbook to guide you in this process. Each factor is listed as a question and invites you to reflect on the family member’s/carer’s status. A few examples are provided for each question.

Once you have completed the cartography, you will have an overview of the family member’s/carer’s situation, which can help you make follow-up decisions. You will be able to answer the following questions:



Does this family member/carer have more *resources* than *barriers*, or vice versa?

Does this family member/carer require a more sustained intervention plan?

If so,

- what resources can be mobilized to support the family member/carer?
- should other professionals or services be recommended to the family member/carer?



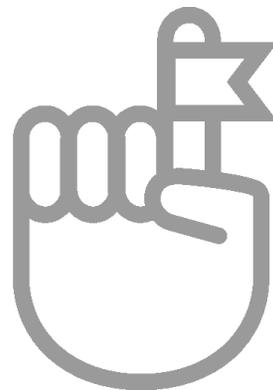
Examples of a positive cartography (a situation where the family member/carer most likely requires little or no follow-up) and a challenging cartography (a situation where the family member/carer almost certainly requires bereavement follow-up) are presented on page 15.

At the end of the handbook, there are spaces for you to note the contact information of key resource persons and your follow-up recommendations.

Option 2: Get an overview of the situation by using the cartography tool as a checklist

You can use the cartography to make sure you have taken into account all of the factors that could influence the family member's/carer's bereavement experience.

For example, you can print the cartography and post it in your workspace or in the team meeting room.



Key considerations when using the cartography tool

The results must be considered in their entirety.

- Factors are not weighted. You should not assume that some are more important than others (except for factors related to complicated grief).
- Your decision-making should not be based on a simple addition of *barriers* and *resources*.
- The situations of the person living with advanced illness and the family member/carer are constantly evolving. Certain *resources* can become *barriers* and vice versa. If necessary, you can use a blank cartography template to reassess the situation.



Your clinical judgement is essential in interpreting results and making decisions. Do not hesitate to share your thoughts and decisions with your team in order to assess the situation and determine what type of support should be offered.



6

Two examples of completed cartographies

The first example shows a **fairly positive** situation requiring little or no support: even though the circumstances of the death are weakening factors, the person has *resources* and there are no complicated grief factors, which means there is little need for specific support.



THE FAMILY MEMBER/CARER <ul style="list-style-type: none"> Age Gender Personality/character Emotional reactions Relationship with the person with advanced illness Mental health Physical health Life projects Problem-solving Understanding Verbal expression Ability to cope with stress Ability to ask for help Meaning given to the illness and death Past caregiving experiences Meaning given to the caregiving experience Outlook on life Spirituality Other _____ 	THE RELATIONSHIP WITH THE INDIVIDUAL WITH ADVANCED ILLNESS <ul style="list-style-type: none"> Nature of the relationship Length of the relationship Communication Living arrangements Emotional aspects Practical support Financial support Other _____ 	THE HEALTH AND SOCIAL SERVICES ENVIRONMENT <ul style="list-style-type: none"> Time between early symptoms and diagnosis Experience between symptoms and diagnosis Time between diagnosis and death Symptom management Quality of information Attentiveness from health and social care professionals Satisfaction with care Do-not-resuscitate order (DNR) Advance medical directives Relationship with the care team(s) Care team(s) consistency Availability of respite care Spiritual support Referral to external resources Post-death follow-up Psychosocial support Home care services Other _____
THE INDIVIDUAL WITH ADVANCED ILLNESS <ul style="list-style-type: none"> Personality/character Age Type of illness Length of illness Meaning given to the illness/death Life projects Spirituality Other _____ 	THE FAMILY MEMBER'S/CARER'S FAMILY <ul style="list-style-type: none"> Recognition of the family member's/carer's role Family cohesion Intrafamilial communication Communication between the family and health and social care system Family adaptability Other _____ 	COMPLICATED GRIEF FACTORS <ul style="list-style-type: none"> Death of a child Violent or brutal death Sudden or prolonged death Repeated losses and separations Current or past mental illness Social isolation Death by suicide Enmeshed relationship with the person with advanced illness
CIRCUMSTANCES OF DEATH <ul style="list-style-type: none"> Anticipation of the death Announcement of the death Place of death Presence at the time of death Nature of the death Other _____ 	THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION <ul style="list-style-type: none"> Employment Work schedule Colleagues Work environment Financial resources Other _____ 	

THE FAMILY MEMBER/CARER <ul style="list-style-type: none"> Age Gender Personality/character Emotional reactions Relationship with the person with advanced illness Mental health Physical health Life projects Problem-solving Understanding Verbal expression Ability to cope with stress Ability to ask for help Meaning given to the illness and death Past caregiving experiences Meaning given to the caregiving experience Outlook on life Spirituality Other _____ 	THE RELATIONSHIP WITH THE INDIVIDUAL WITH ADVANCED ILLNESS <ul style="list-style-type: none"> Nature of the relationship Length of the relationship Communication Living arrangements Emotional aspects Practical support Financial support Other _____ 	THE HEALTH AND SOCIAL SERVICES ENVIRONMENT <ul style="list-style-type: none"> Time between early symptoms and diagnosis Experience between symptoms and diagnosis Time between diagnosis and death Symptom management Quality of information Attentiveness from health and social care professionals Satisfaction with care Do-not-resuscitate order (DNR) Advance medical directives Relationship with the care team(s) Availability of the care team(s) Care team(s) consistency Availability of respite care Spiritual support Referral to external resources Post-death follow-up Psychosocial support Home care services Other _____
THE INDIVIDUAL WITH ADVANCED ILLNESS <ul style="list-style-type: none"> Personality/character Age Type of illness Length of illness Meaning given to the illness/death Life projects Spirituality Other _____ 	THE FAMILY MEMBER'S/CARER'S SOCIAL NETWORK <ul style="list-style-type: none"> Social life Availability of practical support Availability of relational support Neighbours Rituals Spiritual or faith-based support Other _____ 	COMPLICATED GRIEF FACTORS <ul style="list-style-type: none"> Death of a child Violent or brutal death Sudden or prolonged death Repeated losses and separations Current or past mental illness Social isolation Death by suicide Enmeshed relationship with the person with advanced illness
CIRCUMSTANCES OF DEATH <ul style="list-style-type: none"> Anticipation of the death Announcement of the death Place of death Presence at the time of death Nature of the death Other _____ 	THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION <ul style="list-style-type: none"> Employment Work schedule Colleagues Work environment Financial resources Other _____ 	



The second example represents a **rather challenging** situation: even though the characteristics of the family member/carer and their relationship with the person living with advanced illness can be seen as *resources*, the family social network shows several weakening factors. The family member/carer is at a high risk of social isolation following the death (this is a complicated grief factor). Specific support should therefore be planned.

THE FAMILY MEMBER/CARER

- Age
- Gender
- Personality/character
- Emotional reactions
- Relationship with the person with advanced illness
- Mental health
- Physical health
- Life projects
- Problem-solving
- Understanding
- Verbal expression
- Ability to cope with stress
- Ability to ask for help
- Meaning given to the illness and death
- Past caregiving experiences
- Meaning given to the caregiving experience
- Outlook on life
- Spirituality
- Other _____



THE RELATIONSHIP WITH THE INDIVIDUAL WITH ADVANCED ILLNESS

- Nature of the relationship
- Length of the relationship
- Communication
- Living arrangements
- Emotional aspects
- Practical support
- Financial support
- Other _____



THE HEALTH AND SOCIAL SERVICES ENVIRONMENT

- Time between early symptoms and diagnosis
- Experience between symptoms and diagnosis
- Time between diagnosis and death
- Symptom management
- Quality of information
- Attentiveness from health and social care professionals
- Satisfaction with care
- Do-not-resuscitate order (DNR)
- Advance medical directives
- Relationship with the care team(s)
- Availability of the care team(s)
- Care team(s) consistency
- Availability of respite care
- Spiritual support
- Referral to external resources
- Post-death follow-up
- Psychosocial support
- Home care services
- Other _____



THE FAMILY MEMBER'S/CARER'S FAMILY

- Recognition of the family member's/carer's role
- Family cohesion
- Intrafamilial communication
- Communication between the family and health and social care system
- Family adaptability
- Other _____



THE INDIVIDUAL WITH ADVANCED ILLNESS

- Personality/character
- Age
- Type of illness
- Length of illness
- Meaning given to the illness/death
- Life projects
- Spirituality
- Other _____



THE FAMILY MEMBER'S/CARER'S SOCIAL NETWORK

- Social life
- Availability of practical support
- Availability of relational support
- Neighbours
- Rituals
- Spiritual or faith-based support
- Other _____



COMPLICATED GRIEF FACTORS

- Death of a child
- Violent or brutal death
- Sudden or prolonged death
- Repeated losses and separations
- Current or past mental illness
- Social isolation
- Death by suicide
- Enmeshed relationship with the person with advanced illness



CIRCUMSTANCES OF DEATH

- Anticipation of the death
- Announcement of the death
- Place of death
- Presence at the time of death
- Nature of the death
- Other _____



THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION

- Employment
- Work schedule
- Colleagues
- Work environment
- Financial resources
- Other _____



THE FAMILY MEMBER/CARER

- Age
- Gender
- Personality/character
- Emotional reactions
- Relationship with the person with advanced illness
- Mental health
- Physical health
- Life projects
- Problem-solving
- Understanding
- Verbal expression
- Ability to cope with stress
- Ability to ask for help
- Meaning given to the illness and death
- Past caregiving experiences
- Meaning given to the caregiving experience
- Outlook on life
- Spirituality
- Other _____



THE RELATIONSHIP WITH THE INDIVIDUAL WITH ADVANCED ILLNESS

- Nature of the relationship
- Length of the relationship
- Communication
- Living arrangements
- Emotional aspects
- Practical support
- Financial support
- Other _____



THE HEALTH AND SOCIAL SERVICES ENVIRONMENT

- Time between early symptoms and diagnosis
- Experience between symptoms and diagnosis
- Time between diagnosis and death
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- Do-not-resuscitate order (DNR)
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- Availability of respite care
- Spiritual support
- Referral to external resources
- Post-death follow-up
- Psychosocial support
- Home care services
- Other _____



THE FAMILY MEMBER'S/CARER'S FAMILY

- Recognition of the family member's/carer's role
- Family cohesion
- Intrafamilial communication
- Communication between the family and health and social care system
- Family adaptability
- Other _____



THE INDIVIDUAL WITH ADVANCED ILLNESS

- Personality/character
- Age
- Type of illness
- Length of illness
- Meaning given to the illness/death
- Life projects
- Spirituality
- Other _____



THE FAMILY MEMBER'S/CARER'S SOCIAL NETWORK

- Social life
- Availability of practical support
- Availability of relational support
- Neighbours
- Rituals
- Spiritual or faith-based support
- Other _____



COMPLICATED GRIEF FACTORS

- Death of a child
- Violent or brutal death
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- Current or past mental illness
- Social isolation
- Death by suicide
- Enmeshed relationship with the person with advanced illness



CIRCUMSTANCES OF DEATH

- Anticipation of the death
- Announcement of the death
- Place of death
- Presence at the time of death
- Nature of the death
- Other _____



THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION

- Employment
- Work schedule
- Colleagues
- Work environment
- Financial resources
- Other _____



THE FAMILY MEMBER/CARER

- Age
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- Emotional reactions
- Relationship with the person with advanced illness
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- Life projects
- Problem-solving
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- Ability to cope with stress
- Ability to ask for help
- Meaning given to the illness and death
- Past caregiving experiences
- Meaning given to the caregiving experience
- Outlook on life
- Spirituality
- Other _____



THE RELATIONSHIP WITH THE INDIVIDUAL WITH ADVANCED ILLNESS

- Nature of the relationship
- Length of the relationship
- Communication
- Living arrangements
- Emotional aspects
- Practical support
- Financial support
- Other _____



THE HEALTH AND SOCIAL SERVICES ENVIRONMENT

- Time between early symptoms and diagnosis
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- Spiritual support
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- Post-death follow-up
- Psychosocial support
- Home care services
- Other _____



THE FAMILY MEMBER'S/CARER'S FAMILY

- Recognition of the family member's/carer's role
- Family cohesion
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- Communication between the family and health and social care system
- Family adaptability
- Other _____



THE INDIVIDUAL WITH ADVANCED ILLNESS

- Personality/character
- Age
- Type of illness
- Length of illness
- Meaning given to the illness/death
- Life projects
- Spirituality
- Other _____



THE FAMILY MEMBER'S/CARER'S SOCIAL NETWORK

- Social life
- Availability of practical support
- Availability of relational support
- Neighbours
- Rituals
- Spiritual or faith-based support
- Other _____



COMPLICATED GRIEF FACTORS

- Death of a child
- Violent or brutal death
- Sudden or prolonged death
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- Social isolation
- Death by suicide
- Enmeshed relationship with the person with advanced illness



CIRCUMSTANCES OF DEATH

- Anticipation of the death
- Announcement of the death
- Place of death
- Presence at the time of death
- Nature of the death
- Other _____



THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION

- Employment
- Work schedule
- Colleagues
- Work environment
- Financial resources
- Other _____





CARTOGRAPHY HANDBOOK





The family member/carer (1/3)

FACTORS	QUESTIONS	NOTES
Age	Does the family member's/carer's age seem to be a <i>resource</i> or <i>barrier</i> ?	
Gender	Does the family member's/carer's gender seem to be a <i>resource</i> or a <i>barrier</i> ?	
Personality/ character	Does the family member's/carer's personality/character seem to be a <i>resource</i> or <i>barrier</i> ? (optimistic, easy-going, friendly, inflexible, stubborn)	
Emotional reactions	Do the family member's/carer's emotional reactions seem to be a <i>resource</i> or <i>barrier</i> ? (strong, appropriate, absent)	
Relationship with the person with advanced illness	Do you see the relationship between the family member/carer and the individual with advanced illness as a <i>resource</i> or <i>barrier</i> ? (affection, affinity, ambivalence, conflict, mistreatment)	
Mental health	Does the family member's/carer's mental health seem to be a <i>resource</i> or <i>barrier</i> ? (good, poor, under the care of a medical professional) (be sure to note down the contact information of the professional(s) involved)	
Physical health	Does the family member's/carer's physical health seem to be a <i>resource</i> or <i>barrier</i> ? (good, poor, under the care of a medical professional) (be sure to note down the contact information of the professional(s) involved)	





The family member/carer (2/3)

FACTORS	QUESTIONS	NOTES
Life projects	Do the family member's/carer's life projects seem to be a <i>resource</i> or <i>barrier</i> ? (reassessment of projects, disinterest in projects)	
Problem-solving	Does the family member's/carer's problem-solving approach seem to be a <i>resource</i> or <i>barrier</i> ? (flexible, creative, complicated, chaotic)	
Understanding	Does the family member's/carer's ability to understand seem to be a <i>resource</i> or <i>barrier</i> ? (easy, immediate, limited, difficult)	
Verbal expression	Does the family member's/carer's ability to express themselves seem to be a <i>resource</i> or <i>barrier</i> ? (easy, immediate, limited, difficult)	
Ability to cope with stress	Does the family member's/carer's ability to cope with stress seem to be a <i>resource</i> or <i>barrier</i> ? (active, easy, creative, passive, difficult)	
Ability to ask for help	Does the family member's/carer's ability to ask for help seem to be a <i>resource</i> or <i>barrier</i> ? (easy, immediate, limited, difficult)	





The family member/carer (3/3)

FACTORS	QUESTIONS	NOTES
Meaning given to the illness and death	Does the meaning given to the illness and death by the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (positive, self-reproaching)	
Past caregiving experiences	Do past caregiving experiences seem to be a <i>resource</i> or <i>barrier</i> ? (positive, difficult)	
Meaning given to the caregiving experience	Does the meaning given to the caregiving experience seem to be a <i>resource</i> or <i>barrier</i> ? (positive, self-reproach)	
Outlook on life	Does the family member's/carer's outlook on life seem to be a <i>resource</i> or <i>barrier</i> ? (confident, optimistic, defeatist)	
Spirituality	Does the family member's/carer's spirituality seem to be a <i>resource</i> or <i>barrier</i> ? (supportive, guilt-making)	
Other	Are there any other elements specific to the family member/carer that seem to be <i>resources</i> or <i>barriers</i> ? Which ones?	





The individual with advanced illness (1/2)

FACTORS	QUESTIONS	NOTES
Personality/ character	Does the personality/character of the individual seem to be a <i>resource</i> or <i>barrier</i> ? (optimistic, easygoing, friendly, rigid, stubborn)	
Age	Does the age of the individual with advanced illness seem to be a <i>resource</i> or <i>barrier</i> ? (very young, very old)	
Type of illness	Does the type of illness seem to be a <i>resource</i> or <i>barrier</i> ? (cognitive, physical, degenerative)	
Length of illness	Does the length of illness seem to be a <i>resource</i> or <i>barrier</i> ? (chronic, acute, rapid development)	
Meaning given to the illness/death	Does the meaning given by the individual to his or her illness and eventual death seem to be a <i>resource</i> or <i>barrier</i> ? (positive, self-reproaching)	
Life projects	Do the individual's life projects seem to be a <i>resource</i> or <i>barrier</i> ? (adaptation of projects, lack of interest in projects)	





The individual with advanced illness (2/2)

FACTORS	QUESTIONS	NOTES
Spirituality	Does the individual's spirituality seem to be a <i>resource</i> or <i>barrier</i> ? (supportive, guilt-making)	
Other	Are there any other elements specific to the individual that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	





Circumstances of death

FACTORS	QUESTIONS	NOTES
Anticipation of the death	Does the family member's/carer's anticipation (or not) of death seem to be a <i>resource</i> or <i>barrier</i> ? (anticipation experienced positively, unexpected death)	
Announcement of the death	Does the way the death was announced to the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (supportive, abrupt)	
Place of death	Does the individual's place of death seem to be a <i>resource</i> or <i>barrier</i> ? (relief, disappointment)	
Presence at the time of death	Does the presence (or absence) of the family member/carer at the time of death seem to be a <i>resource</i> or <i>barrier</i> ? (positive experience, difficult experience)	
Nature of the death	Does the manner in which the individual died seem to be a <i>resource</i> or <i>barrier</i> ? (medical aid in dying with shared decision-making or not)	
Other	Are there any other elements surrounding the death that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	





The relationship with the individual with advanced illness (1/2)

FACTORS	QUESTIONS	NOTES
Nature of the relationship	Does the nature of relationship between the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (marriage, parent-child, friendship)	
Length of the relationship	Does the length of the relationship between the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (new relationship, long-term relationship Note: a short-term relationship does not necessarily mean limited emotional investment)	
Communication	Does the type of communication between the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (open, difficult, things left unsaid)	
Living arrangements	Do the living arrangements of the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (cohabitation, semi-cohabitation, geographical distance)	
Emotional aspects	Do the emotional ties between the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (conflicts, tensions, affection)	
Practical support	Does the practical support between the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (positive, insufficient, negative)	

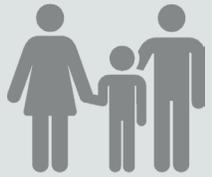




The relationship with the individual with advanced illness (2/2)

FACTORS	QUESTIONS	NOTES
Financial support	Does the financial support between the individual with advanced illness and the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (positive, insufficient, negative)	
Other	Are there other elements of the relationship that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	





The family member's/carer's family

FACTORS	QUESTIONS	NOTES
Recognition of the family member's/carer's role	Is the family member/carer recognized in his or her role by those in the immediate environment?	
Family cohesion	Does family cohesion seem to be a <i>resource</i> or <i>barrier</i> ? (flexible, enmeshed, fragile)	
Intrafamilial communication	Does communication among the family members seem to be a <i>resource</i> or <i>barrier</i> ? (open, positive, closed, non-existent)	
Communication between the family and health and social care system	Does the quality of communication between the family and health and social care system seem to be a <i>resource</i> or <i>barrier</i> ? (open, positive, closed, non-existent)	
Family adaptability	Does the family's adaptability seem to be a <i>resource</i> or <i>barrier</i> ? (strong, medium, weak)	
Other	Are there other elements related to the family that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	





The family member's/carer's social network

FACTORS	QUESTIONS	NOTES
Social life	Does the quality of the family member's/carer's social life seem to be a <i>resource</i> or <i>barrier</i> ? (fulfilling, limited, diminished)	
Availability of practical support	Does the practical support available to the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (bringing meals over, helping with laundry, walking the dog) (present, invasive, absent)	
Availability of relational support	Does the relational support available to the family member/carer seem to be a <i>resource</i> or <i>barrier</i> ? (phone, face-to-face) (presence, attentiveness, empathy, distance, conflict)	
Neighbours	Can neighbours offer additional help? (run errands, shovel snow)	
Rituals	Do the family member's/carer's rituals seem to be a <i>resource</i> or <i>barrier</i> ? (meditation, light a candle in memory of the deceased)	
Spiritual or faith-based support	Does the family member/carer have ties to a spiritual or faith-based group and does this seem to be a resource or barrier? (supportive, guilt-making, invasive)	
Other	Are there any other elements in the family member's/carer's relational environment that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	





The family member's/carer's professional and financial situation

FACTORS	QUESTIONS	NOTES
Employment	Does the family member's/carer's job situation seem to be a <i>resource</i> or <i>barrier</i> (employee assistance program, employment insurance) (Note: for some person, being unemployed can be a <i>resource</i> , despite the loss of income)	
Work schedule	Does the family member's/carer's work schedule seem to be a <i>resource</i> or <i>barrier</i> ? (night shift, split shift, on call)	
Colleagues	Do the family member's/carer's colleagues seem to be a <i>resource</i> or <i>barrier</i> ? (supportive, understanding, unpleasant, unsupportive)	
Work environment	Does the family member's/carer's work environment seem to be a <i>resource</i> or <i>barrier</i> ? (flexible hours, rigid environment)	
Financial resources	Does the family member's/carer's financial situation seem to be a <i>resource</i> or <i>barrier</i> ? (stable or significant drop in standard of living, stable or reduced quality of life, financial support from family and friends)	
Other	Are there other specific elements in the family member's/carer's professional or financial situation that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	





The health and social services environment (1/3)

FACTORS	QUESTIONS	NOTES
Time between early symptoms and diagnosis	Does the time between early symptoms and the diagnosis seem to be a <i>resource</i> or <i>barrier</i> ? (too long, too short)	
Experience between symptoms and diagnosis	Does the person's experience between symptoms and diagnosis seem to be a <i>resource</i> or <i>barrier</i> ? (uncertainty, worry, anxiety, frustration, shock)	
Time between diagnosis and death	Does the time between the diagnosis and death seem to be a <i>resource</i> or <i>barrier</i> ? (too long, too short)	
Symptom management	Does the management of symptoms seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, inadequate)	
Quality of information	Does the quality of the information provided seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, inadequate)	
Attentiveness from health and social care professionals	Does the attentiveness of professionals seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, inadequate)	
Satisfaction with care	Does the person's satisfaction with the care received seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, inadequate)	





The health and social services environment (2/3)

FACTORS	QUESTIONS	NOTES
Do-not-resuscitate order (DNR)	Does the quality of information concerning the do-not-resuscitate order (DNR) seem to be a <i>resource</i> or <i>barrier</i> ? (good, inadequate) (be sure to note any relevant documents and resource persons)	
Advance medical directives	Does the quality of information concerning advance medical directives seem to be a <i>resource</i> or <i>barrier</i> ? (good, inadequate) (be sure to note any relevant documents and resource persons)	
Relationship with the care team(s)	Does the quality of the relationship between the person and the care team(s) seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, poor)	
Availability of the care team(s)	Does the availability of the care team(s) seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, inadequate)	
Care team(s) consistency	Does the care team consistency seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, absent)	
Availability of respite care	Does the availability of respite care seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, absent)	
Spiritual support	Does available spiritual support seem to be a <i>resource</i> or <i>barrier</i> ? (present, absent)	





The health and social services environment (3/3)

FACTORS	QUESTIONS	NOTES
Referral to external resources	Does the quality of referral to external resources seem to be a <i>resource</i> or <i>barrier</i> ? (good, average, absent)	
Post-death follow-up	Is there a post-death follow-up plan in place? (yes, no)	
Psychosocial support	Is the family member/carer receiving sufficient psychosocial support? (yes, no)	
Home care services	Are the home care services provided sufficient? (presence of a dedicated palliative care team)	
Other	Are there other specific elements in the health and social services environment that seem to be a <i>resource</i> or <i>barrier</i> ? Which ones?	



COMPLICATED GRIEF FACTORS	TO BE CHECKED	NOTES
Death of a child		
Violent or brutal death		
Sudden or prolonged death		
Repeated losses and separations		
Current or past mental illness		
Social isolation		
Death by suicide		
Enmeshed relationship with the person with advanced illness		



CONTACT INFORMATION

	NAME	PHONE NUMBER
Doctor		
Nurse		
Social worker/ Psychosocial Practitioner		
Psychologist		
Spouse/Partner		
Children		
Chosen family		
Others		



FOLLOW-UP (1/2)

Name of the family member/carer: _____

Date of birth: _____

Date of completion of the cartography tool (if relevant): _____

Description of the current situation: _____

DECISIONS TAKEN:

- Do the identified *barriers* involve complicated grief factors? If so, does the family member/carer require professional support?



FOLLOW-UP (2/2)

-
- Are there more *resources* than *barriers*?

-
-
- Even if there are few *barriers*, are they still likely to make the person's grieving process more difficult?

-
-
- Description of the family member's/carer's *resources*

-
-
- Description of problems/issues identified (if applicable)
-
-



THE FAMILY MEMBER/CARER

- Age
- Gender
- Personality/character
- Emotional reactions
- Relationship with the person with advanced illness
- Mental health
- Physical health
- Life projects
- Problem-solving
- Understanding
- Verbal expression
- Ability to cope with stress
- Ability to ask for help
- Meaning given to the illness and death
- Past caregiving experiences
- Meaning given to the caregiving experience
- Outlook on life
- Spirituality
- Other _____



THE RELATIONSHIP WITH THE INDIVIDUAL WITH ADVANCED ILLNESS

- Nature of the relationship
- Length of the relationship
- Communication
- Living arrangements
- Emotional aspects
- Practical support
- Financial support
- Other _____



THE HEALTH AND SOCIAL SERVICES ENVIRONMENT

- Time between early symptoms and diagnosis
- Experience between symptoms and diagnosis
- Time between diagnosis and death
- Symptom management
- Quality of information
- Attentiveness from health and social care professionals
- Satisfaction with care
- Do-not-resuscitate order (DNR)
- Advance medical directives
- Relationship with the care team(s)
- Availability of the care team(s)
- Care team(s) consistency
- Availability of respite care
- Spiritual support
- Referral to external resources
- Post-death follow-up
- Psychosocial support
- Home care services
- Other _____



THE FAMILY MEMBER'S/CARER'S FAMILY

- Recognition of the family member's/carer's role
- Family cohesion
- Intrafamilial communication
- Communication between the family and health and social care system
- Family adaptability
- Other _____



THE INDIVIDUAL WITH ADVANCED ILLNESS

- Personality/character
- Age
- Type of illness
- Length of illness
- Meaning given to the illness/death
- Life projects
- Spirituality
- Other _____



THE FAMILY MEMBER'S/CARER'S SOCIAL NETWORK

- Social life
- Availability of practical support
- Availability of relational support
- Neighbours
- Rituals
- Spiritual or faith-based support
- Other _____



COMPLICATED GRIEF FACTORS

- Death of a child
- Violent or brutal death
- Sudden or prolonged death
- Repeated losses and separations
- Current or past mental illness
- Social isolation
- Death by suicide
- Enmeshed relationship with the person with advanced illness



CIRCUMSTANCES OF DEATH

- Anticipation of the death
- Announcement of the death
- Place of death
- Presence at the time of death
- Nature of the death
- Other _____



THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION

- Employment
- Work schedule
- Colleagues
- Work environment
- Financial resources
- Other _____



THE FAMILY MEMBER/CARER

- Age
- Gender
- Personality/character
- Emotional reactions
- Relationship with the person with advanced illness
- Mental health
- Physical health
- Life projects
- Problem-solving
- Understanding
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THE FAMILY MEMBER'S/CARER'S PROFESSIONAL AND FINANCIAL SITUATION

- Employment
- Work schedule
- Colleagues
- Work environment
- Financial resources
- Other _____



9

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