



**GIVINGCARE**  
Empowering Caregivers

A2.2 – Educative resources for teachers

## Bereavement

Module: End of Life Care

Sub-Module: Bereavement/ Mourning and Family Support



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# Lesson Outcomes

- 1 - Understanding the general concepts related to life cycle
- 2 - Identifying the different types of losses and its impacts in important others
- 3 - Understanding the cultural aspects and differences in mourning
- 4 - Identifying main concepts and techniques in grief counselling

# Topics

- 1.1 - Systems and life cycle
- 1.2 - Types of losses – Attachment Theory
  - Loss and Important Others
  - Death of a Parent
  - Death of a Child
  - Death of a Sibling
  - Death of a Companion
  - Suicide
  - Anticipatory grief
- 1.3 - Mourning in Different Cultures
  - Rituals and Meaning
- 1.4 - End of Life Issues
  - Difficult Conversations
- 1.5 - Grief Counselling

# Introduction

<b>Module</b>	End of Life Care
<b>Sub-module</b>	Mourning and Family Support
<b>Lesson nr.</b>	#1
<b>Duration</b> (minutes)	90 min
<b>Date</b>	To be defined

# 1.1 - Systems and life cycle

[https://www.youtube.com/watch?v=DHBgTFHjPXI&ab\\_channel=TheNewYorkTimes](https://www.youtube.com/watch?v=DHBgTFHjPXI&ab_channel=TheNewYorkTimes)

[https://www.youtube.com/watch?v=aZdDXNmD9wk&ab\\_channel=TheGuardian](https://www.youtube.com/watch?v=aZdDXNmD9wk&ab_channel=TheGuardian)

# 1.1 - Systems and life cycle

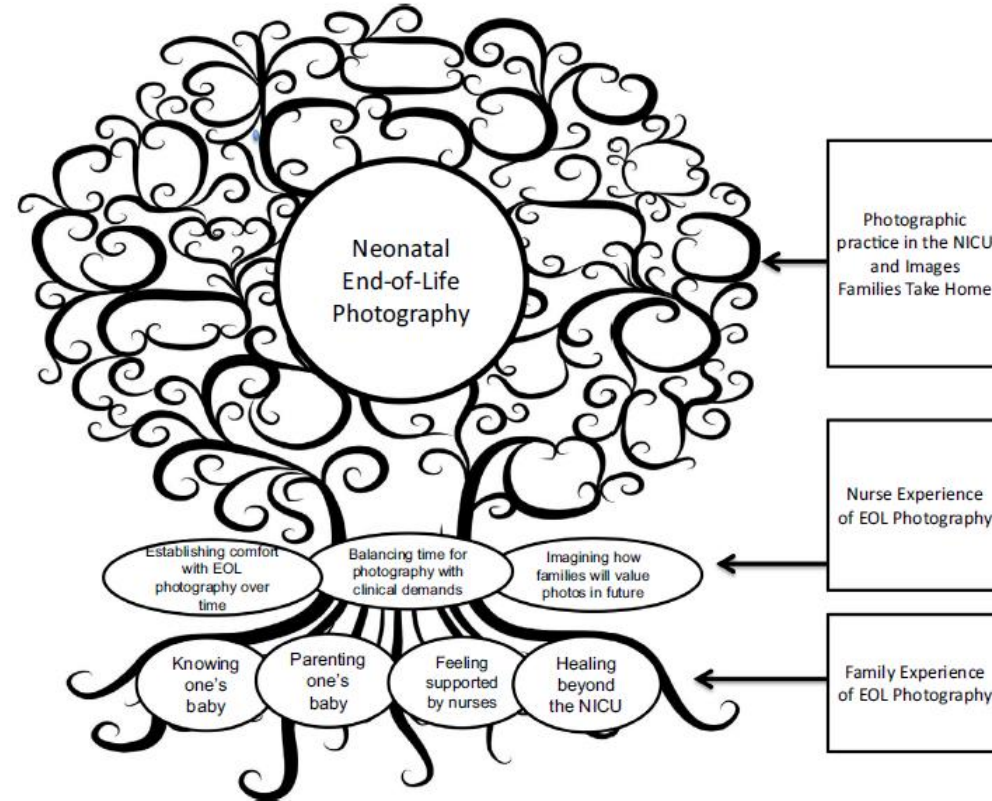


Fig. 1. A model for photographing living relationships in the NICU.

Please cite this article as: Martel, S., & Ives-Baine, L., Nurses' Experiences of End-of-life Photography in NICU Bereavement Support, *Journal of Pediatric Nursing* (2018), <https://doi.org/10.1016/j.pedn.2018.05.011>

# 1.1 - Systems and life cycle

Supportive Care in Cancer (2020) 28:4131–4139  
<https://doi.org/10.1007/s00520-019-05249-3>

ORIGINAL ARTICLE



Reconsidering early parental grief following the death of a child from cancer: a new framework for future research and bereavement support

Jennifer Snaman<sup>1,2,3</sup> · Sue E. Morris<sup>1,4,5</sup> · Abby R. Rosenberg<sup>6,7</sup> · Rachel Holder<sup>1</sup> · Justin Baker<sup>8</sup> · Joanne Wolfe<sup>1,3</sup>

**Table 2** Factors associated with physical and mental health outcomes in parents following the death of a child from cancer. Baseline factors/considerations are mostly stable; modifiable factors may be possible targets for interventions

	Baseline factors/considerations	Modifiable factors
Individual factors—parent	Age	Trust in care team
	Gender	Psychosocial support during treatment
	Race/ethnicity	Resilience
	Education	Mechanisms of coping
	Income/financial strain	Post-traumatic growth
	Preexisting medical issues	Meaning-making
	Preexisting mental health issues	Depressive symptoms
Individual factors—child		Symptoms of anxiety
		Post-traumatic stress symptoms
		Prolonged grief
		Substance/alcohol use
		Decisional regret
		Financial strain
		Location of death (actual, planned)
Interpersonal factors	Age at death	Symptoms or suffering at the end-of-life
	Cancer diagnosis/prognosis	Moment of death (difficult, peaceful)
	Length of illness	Quality of life at the end-of-life
	Treatment type/intensity	Family dynamics/functioning
	Marital status primary caregiver	Communication between patient/family and team
		Anticipatory guidance/preparation
		Hospice involvement
	Palliative care involvement	
	Social support	
	Isolation	
	Continuing bonds	
	Social functioning and integration	

# 1.1 - Systems and life cycle

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**Table 3.** Unanswered questions related to parental psychological and mental health outcomes following the death of a child and intervention development and assessment

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#### Questions related to factors and interactions

- What other factors may be important to assess?
- What is the role of social media on the parental grief experience?
- Interactions between various factors (can parents with depressive symptoms also have higher levels of social functioning? At what level of severity do these depressive symptoms impact personally relevant social functioning?)
- What is the degree of impact of different factors on parental outcomes (i.e., are certain factors more important than others)?
- How do these factors change over time?

#### Questions related to intervention development and assessment

- What is the correct time to intervene/provider additional support to improve parental outcomes?
- What does a supportive intervention for bereaved parents of children that died from cancer entail? At what “dose”?
- How can you motivate those parents that may benefit from additional supportive interventions to participate?
- What are the “correct” outcomes to measure? (what are we trying to change? Is this different for every individual? If so, how do we assess the impact of interventions?)

#### Questions related to similarities/differences between different parent populations

- How do outcomes in parents of children who died from cancer differ from other bereaved parents of children with complex medical issues?
  - How do outcomes of bereaved parents differ from parents of children that were treated for cancer and survived (i.e., to what degree are the psychosocial outcomes the result of having a child that was treated for cancer vs. a child that died from cancer?)
  - Would parents of children with different illness experiences benefit from similar supportive interventions?
-



# Introduction

<b>Module</b>	End of Life Care
<b>Sub-module</b>	Mourning and Family Support
<b>Lesson nr.</b>	#2
<b>Duration</b> (minutes)	90 min
<b>Date</b>	To be defined

# 1.2 - Types of losses

## **Anticipatory Grief:**

- Preparation of the next loss.
- It is experienced both by patients and family members
- It helps to become aware of what is going on and to imagine life without being loved.
- Sometimes people think with guilt about concrete things: the burial, the cemetery, etc
- It has its positive valence.

# 1.2 - Types of losses

## Grief in children



The concept of death is abstract and as such it is difficult to explain to children how they move on concrete.

# 1.2 - Types of losses

## Grief in children



Age is crucial for inferring the reality of death.

Age

culture,

education,

Society

Religion

# 1.2 - Types of losses

## Grief in children

similarities between grief in children and grief in adults



Grief in children	Grief in adults
Children experience grief.	Adults experience grief.
Some children need help making it.	Some adults need help making it.
Grief over the loss of a loved one floods the child with sadness.	Grief over the loss of a loved one floods the adult with sadness.
The child expresses his sorrow with crying.	The adult expresses his sorrow with crying.

# 1.2 - Types of losses

## Grief in children

differences between grief in children and grief in adults



Grief in children	Grief in adults
Children do not withdraw.	Adults withdraw.
Children become insistent and demanding.	Adults want nothing more than to be alone with their pain.
They are looking for a substitute so as not to lose security.	The adult takes a long time to open up to new relationships.
They need to check that their needs will be met.	The adult takes time to satisfy his needs.

# 1.2 - Types of losses

## Grief in children

differences between grief in children and grief in adults



Grief in children	Grief in adults
The child has fluctuating and variable emotions: anger, grief, anxiety, confusion, joy, laughter, illusion ...	The adult has more permanent and stable emotions.
Its tonic is not permanent sadness. They can laugh, play, jump ...	Its tonic is permanent sadness.
The child allows himself to enjoy.	The adult feels that he betrays the deceased if he enjoys.

# 1.2 - Types of losses

## Grief in children

differences between grief in children and grief in adults



Grief in children	Grief in adults
The child's mourning may be longer, due to its evolutionary changes.	Normal adult grief is shorter.
We do not allow the child to "be sad."	We hope that the adult "is sad."
The child wants to know everything.	The adult tries not to say anything.
The child perceives the pain and realizes that someone important is missing.	The adult hides the grief from the child trying to make him believe that "everything is the same."



# 1.2 - Types of losses



Frequent errors

**Be aware that:**

don't compare losses  
time doesn't cure

# 1.2 - Types of losses

## How to talk to the child about death?

The reality of death.

What happened, but globally.

Don't go into horrible and painful detail.

If the child asks for details, respond sensitively and give importance to the loss, not the detail.

We are with him, we want him, we understand his pain.

That you are free to say and express what you feel and that you can make it free

# Introduction

<b>Module</b>	End of Life Care
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<b>Lesson nr.</b>	#3
<b>Duration</b> (minutes)	90 min
<b>Date</b>	To be defined

# 1.3 - Mourning in Different Cultures



Dublin City Gallery, The Hugh Lane, Ireland / The Bridgeman Art Library

*The Widow* (1882) by Frank O'Meara

# 1.3 - Mourning in Different Cultures

*In March, 2011, my wife died and I experienced the physiology of grief. I felt greatly sad and yearned for her. I didn't sleep well. When I returned to a now empty house, I became agitated. I also felt fatigued and had difficulty concentrating on my academic work. My weight declined owing to a newly indifferent appetite. This dark experience lightened over the months, so that the feelings became much less acute by around 6 months. But after 46 years of marriage, it will come as no surprise to most people that as I approach the first anniversary of my loss, I still feel sadness at times and harbour the sense that a part of me is gone forever. I'm not even sure my caregiving for my wife, who died of Alzheimer's disease, ended with her death. I am still caring for our memories. Is there anything wrong (or pathological) with that?*

Arthur Kleinman  
[www.thelancet.com](http://www.thelancet.com) Vol 379 February 18, 2012

# 1.3 - Mourning in Different Cultures

The experience of loss is never out of context.

Meanings

Values

Age

Gender

Financial and work conditions

What is happening in one's life and in the world...

[https://www.youtube.com/watch?v=JPcp58i\\_5Nw&ab\\_channel=OpenLearnfromTheOpenUniversity](https://www.youtube.com/watch?v=JPcp58i_5Nw&ab_channel=OpenLearnfromTheOpenUniversity)

# 1.4 - End of Life Issues

Difficult Conversations

## **Bad news?**

# 1.4 - End of Life Issues

Difficult Conversations

## **Bad news?**

*Any information that involves a drastic change in the perspective of the future, in a negative sense.*

Buckman



# 1.4 - End of Life Issues

Bad news

To say or not to say?

## 1.4 - End of Life Issues

Bad news. To say or not to say?  
**arguments against**

There is no certainty regarding the diagnosis / prognosis

It's cruelty without benefits

The patient can give up on living (risk of suicide)

Risk of demoralization and not fighting, contributing to a faster death

Professional failure

# 1.4 - End of Life Issues

Bad news. To say or not to say?  
**arguments in favor**

Right to the truth / Respect for the other  
Allow to live this phase of life as you wish  
Allow important decisions to be made  
Allow to take stock of life  
Promote autonomy through information

# 1.4 - End of Life Issues

<https://www.youtube.com/watch?v=juKAMBh9J54>

<https://www.youtube.com/watch?v=KtjTr12Ovpk>

# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

- 1 – Preparation
- 2 – Find out what the patient knows
- 3 – Find out what the patient wants to know
- 4 – Share the information
- 5 – Responding to the patient's emotions
- 6 – Plan the follow-up

# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

## 1 – Preparation

Choosing the right place  
have time  
choose who should be

# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

Buckman R, 2001

2 – Find out what the patient knows

*"Are you worried about your health condition?"*

*"What do you think about the pain and vomiting you've been experiencing?"*

To perceive:

What does the patient understand about the disease

How to express

The emotional content of patient messages

# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

Buckman R, 2001

3 – Find out what the patient wants to know

Search the level of knowledge

*"It's nothing serious, is it?"*

*"If at any time it is discovered that your illness is serious, will you want to know?"*

*"Would you like to be given all the details of your diagnosis?"*

It may be time for exposing doubts.



# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

Buckman R, 2001

## 4 – Share the information

decide the agenda

break the news gradually

use the warning shot

accept the denial but not condone it

avoid long sentences

avoid using technical terms

speak simply and clearly

# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

Buckman R, 2001

## 5 – Responding to the patient's emotions

If we can't understand emotions, we have more problems to solve.

Fear?

Despair?

Angry?

Aggressiveness

cry

Sadness

### **Validate emotional reaction**

Do not lie

Not making predictions about death

do not give false hope

Allow realistic hope (cross fingers)

# 1.4 - End of Life Issues – bad news

S	<i>Setting up</i>
P	<i>Perception</i>
I	<i>Invitation</i>
K	<i>Knowledge</i>
E	<i>Emotions</i>
S	<i>Strategy and Summary</i>

Buckman R, 2001

## 6 – Plan the follow-up

Provide action plan for the future

Consensual main problems

Realization of important aspects for the patient

Who else needs to know?

Plan next meeting

Contacts

# Introduction

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<b>Lesson nr.</b>	#4
<b>Duration</b> (minutes)	90 min
<b>Date</b>	To be defined

## 1.5 - Grief Counselling

Care takes place in life history, in encounters and in relationships.

# Bereavement

Adaptation process

Feelings, emotions, behaviors

**5 bereaved for every adult who dies, 7 bereaved for every child**

Cohen J, Deliens L. Applying a public health perspective to end-of-life care. In: Cohen J, Deliens L, editors. A Public Health Perspective on End-of -Life Care. Oxford: Oxford University Press; 2012. p. 3–18

# Bereavement

It implies "elaborating the pain"

*"Learning to think without guilt about the loss, expressing the feelings it provokes, sharing them in an atmosphere of respect and without obsessions, analyzing the consequences that this loss entails and putting into practice behaviors that allow you to face life in all its richness". (Ezequiel Sanchez)*

# Bereavement

Normal, highly personal response to the death of a loved one, involving all domains of human experience: physical, psychological, spiritual, and social

It is a natural process that fulfills the main objective: **adaptation**



# Bereavement

## During the disease process

Anticipatory grief

Assessment of risk factors

## Last days and hours or life

Bad news

## After death

Facilitate adaptation

Information

Follow-up

# Bereavement frequent manifestations

Shock

Denial

Sadness

Depression

Fault

Rage

Anxiety

Disinterest in your surroundings

Acceptance

Physical manifestations (tachycardia, palpitations, nausea, changes in AT, etc.)

# Bereavement frequent manifestations

## Sensations

Empty stomach, sensitivity to noise, sense of depersonalization, dry mouth

## Thoughts

Disbelief, worry, confusion, sense of the deceased's presence, hallucinations

# Risk Factors

Nature of the relationship

Vulnerability

Circumstances of loss

Object characteristics

Family and social support

Problematic contact with health services

# Risk Factors

Nature of the relationship

Overly dependent

Ambivalent

# Risk Factors

## **Vulnerability**

Psychiatric Disorder

Personality and Coping Style

Binding style

Accumulated experience of personal losses

# Risk Factors

## **Circumstances of loss**

Sudden and unexpected

Traumatic

Stigmatized

# Risk Factors

## **Object characteristics**

Mom

Son

Childhood

Brother



# Risk Factors

## **Family and social support**

Family dysfunction

Isolation

Alienation

Changed projects

# Risk Factors

## **Problematic contact with health services**

Lack of symptom control

Difficulties or delay in diagnosis

Dysfunctional relationships with health professionals

Therapeutic obstinacy

# Intervention Proposals

## AIM

Accept the reality of loss

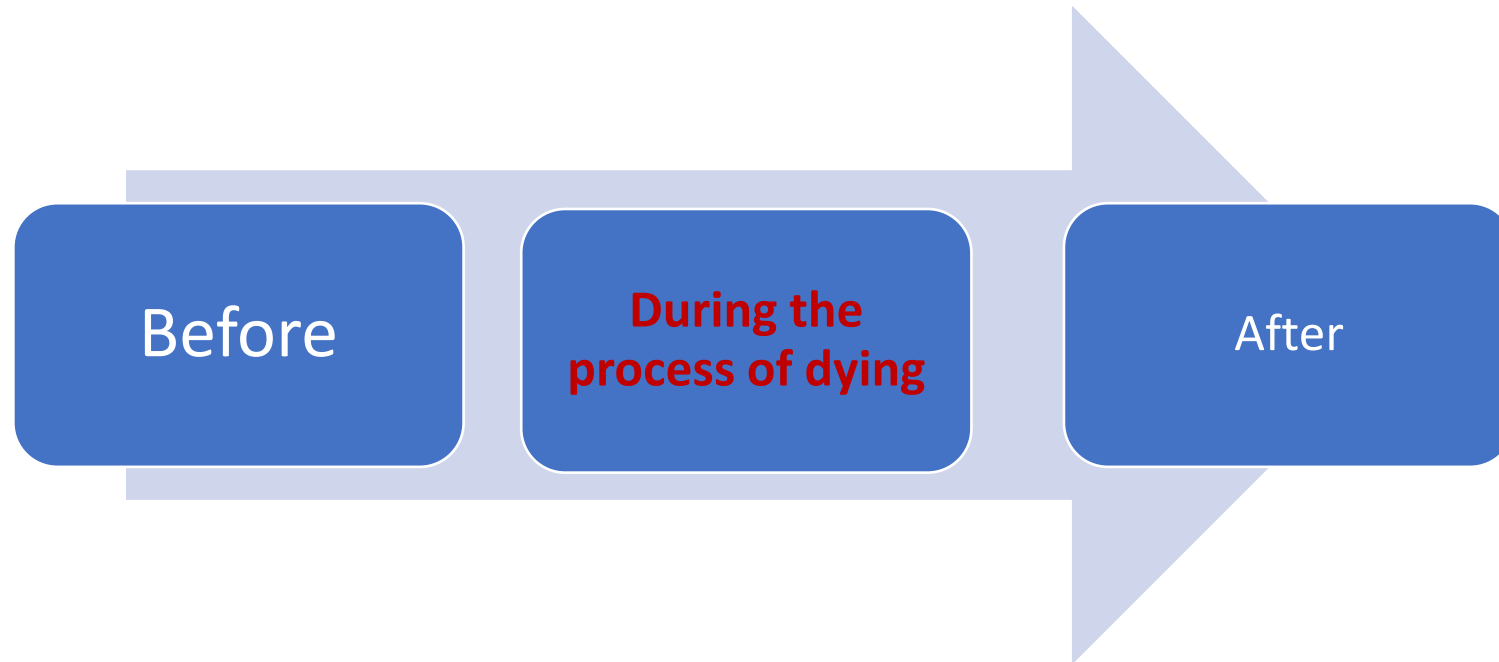
Give expression to feelings

Adapt to the environment in which the deceased is no longer

Investing emotional energy in other relationships

Cultivate hope

# Intervention Proposals



# Intervention Proposals

Try not to say:

*At least you have other children  
God wanted a little angel  
I know how you feel  
It's better that way, no longer suffering  
If it had to happen, thank goodness it was fast  
It's God's Will  
Jesus also suffered  
It is the law of life  
He / She was too good for this world  
Time heals all wounds*

# Intervention Proposals

Assess the risk of bereavement disorder early in the approach taken to the family and document.

Written information / guide / brochure

Telephone contact 1 month after the patient's death, maintaining full availability for previous contacts, if the family wishes to do so.

Schedule new contacts if necessary.

Proceed to referral to psychology / psychiatry, if necessary.

Send condolence card

# Intervention Proposals

**Allow expression of emotions, feelings, thoughts**

Validate

Talking about possible manifestations as natural

Promote self-care

Facilitate contact with support structures

Key dates

Strategies

# Intervention Proposals

***We don't "move on" from grieve, we move forward with it.***

[https://l.messenger.com/l.php?u=https%3A%2F%2Fwww.ted.com%2Ftalks%2Fnora\\_mcinerny\\_we\\_don\\_t\\_move\\_on\\_from\\_grief\\_we\\_move\\_forward\\_with\\_it%23t-72919&h=AT3zy2zpXo\\_8ij5ngkLTuSkoP3jJyd-RPqgyyB-n9idISfclAWDR\\_Smtrx517Xy76cK7eQHvzbRQ2mxgWQuTq5986L2Ytw\\_gg3yUNYE6vLiXJQkUZQEMx-PRYyByO8fwLg](https://l.messenger.com/l.php?u=https%3A%2F%2Fwww.ted.com%2Ftalks%2Fnora_mcinerny_we_don_t_move_on_from_grief_we_move_forward_with_it%23t-72919&h=AT3zy2zpXo_8ij5ngkLTuSkoP3jJyd-RPqgyyB-n9idISfclAWDR_Smtrx517Xy76cK7eQHvzbRQ2mxgWQuTq5986L2Ytw_gg3yUNYE6vLiXJQkUZQEMx-PRYyByO8fwLg)



# Conclusion

**HERE ARE SOME THINGS  
TO REMEMBER:**

**THERE IS NO FINISH LINE.  
THIS IS NOT A RACE.**

**GRIEF HAS  
ITS OWN LIFESPAN,  
UNIQUE TO YOU.**

@REFUGEINGRIEF



**GIVINGCARE**  
Empowering Caregivers

Thank you!

Teachers's name

Teachers e-mail

Date of the session

