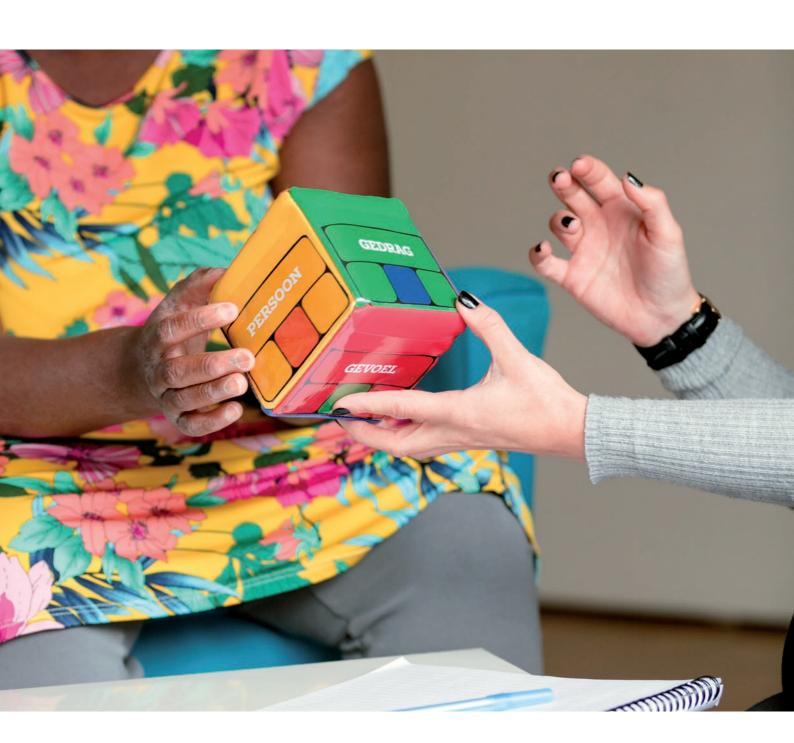
MANUAL

THE GRIEF CUBE

A TOOL FOR DEALING WITH LOSS, BEREAVEMENT AND GRIEF



Amerpoort



INTRODUCTION

This is the manual for the Grief Cube, a tool for dealing with loss, bereavement and grief. The Grief Cube is the result of a study that took place at Amerpoort and Sherpa in 2017 and 2018. It is intended for service users, relatives and staff who want to talk to each other about loss, bereavement and grief. The Grief Cube can be used in a personal conversation, but also during a team meeting.

This manual contains the explanation of the Grief Cube. It has three appendixes that may be useful when using the Cube.

The Grief Cube can be ordered from www.senso-care.nl/rouwkubus



What is loss, bereavement and grief?

Everybody experiences loss in their lives. Loss can involve the death of a loved one (bereavement), but also moving house, the end of a relationship or growing older. Service users often have to deal with group changes or staff who leave the facility. Service users can also feel 'different' and experience this as a loss. Relatives and staff face the deaths of service users or group changes. Grief is about dealing with loss. Being forced to adjust to a new situation. This process is different for each individual. It is important to recognise what constitutes a loss to you and to another person. Recognising and acknowledging loss allows you to provide support to yourself and others in dealing with grief.

What is the Grief Cube?

The Grief Cube is a dice with coloured sides.

Each side of the cube has a word on it that is linked to specific questions. These words and questions can be found on page 5. The Grief Cube is a tool to facilitate talking about loss, bereavement and grief. It can help you find out what you or another person needs. The Grief Cube, just like Rubik's Cube, resembles a puzzle. It looks that way because grief can feel like a puzzle: how do I solve this? The Grief Cube is actually a puzzle that doesn't need solving. It helps when grief is simply allowed to exist. It is precisely looking at loss, bereavement and grief from all angles that makes a person feel heard and seen.

For who is the Grief Cube intended?

The Grief Cube is intended for service users, relatives and staff who want to discuss loss, bereavement and grief. The cube can be used to discuss another person's loss. But it can also be used to look at yourself and who you really are. If you want to help somebody else, you do well to reflect on who you are. Your background and history affect the things that you say and do. Your own experiences can help you to better understand another person. But they can also make you overlook things.

Because grief is so very personal, you may find it unpleasant to talk about it to other people. Discussing the Grief Cube doesn't require you to share everything if you don't want to. But you should be aware of this. If you are a staff member or relative who finds grief to be an uncomfortable subject, you may not be able to actually be there for the service user. Together, you can then discuss who can be. As a service user, you can indicate with whom you want to discuss the Grief Cube. They can be a staff member but also, for instance, a relative or a friend.

How do you use the Grief Cube?

The cube can be used in a personal conversation but also in a team meeting. It may be a good idea to first reflect on the answers yourself before discussing them with each other. In appendix 1 you will find a form for filling out the answers. You can discuss the different sides of the cube one after the other or use the cube as a dice. Sometimes the conversation can suddenly shift from one side of the cube to another. The discussion leader can point this out and turn up the relevant side of the cube. It is important for the discussion leader to ask open questions and follow up on them.

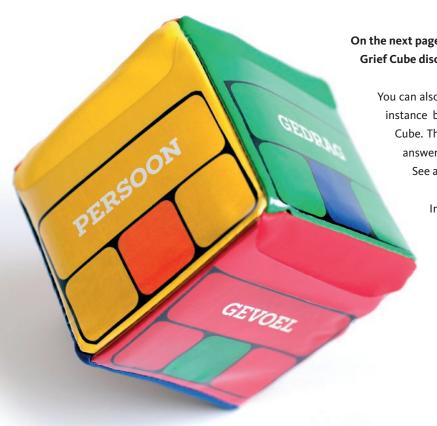
The transparent card holders make it possible to adjust the Grief Cube to different people. You could, for instance put photos, pictograms or drawings into the holders attached to the different sides. Or you could take out the yellow card that says 'person' and write the person's name on the plastic with a whiteboard marker.

It is a good idea to conclude the conversation with the 'support' side of the cube. It allows you to think together about what a person needs. The answer may also be that nothing needs to be done.



- > Involve the service user and his or her family. Whenever possible, involve the service user in the conversation. The service user knows best what he or she needs. When the service user is agreeable, also involve his or her relatives in the Grief Cube conversation. Relatives often have valuable information on a service user's background. When a service user is unable to take part in a discussion, you can fill in the questions on their behalf.
- Inform the behavioural scientist: It is advisable to inform the behavioural scientist about your intended use of the Grief Cube. He or she can give you advice based on professional expertise.
- > Find a discussion leader for your group discussion: a discussion leader with knowledge of, and experience with loss,

- bereavement and grief is recommended for a group conversation. He or she can answer any questions about loss, bereavement and grief and think along about grief support.
- > Make a follow-up appointment: When making appointments about grief support, it is advisable to plan another meeting about three months later (or earlier if necessary). The Grief Cube can then be used to determine how things are going and whether some action needs to be taken.
- Need ideas or materials for grief counselling? Ask a pastoral counsellor or grief and loss counsellor from within your organisation for advice. They can think along about what you can do and where to find materials.



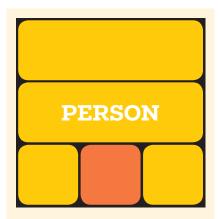
On the next page you will find helpful questions for your Grief Cube discussion arranged by subject.

You can also share these questions ahead of time, for instance before a team discussion with the Grief Cube. The participants can then write down their answers and bring them to the team discussion.

See appendix 1 for an answer form.

In appendix 2 you will find a short explanation in plain language. You could possibly also show these pages during your discussion.



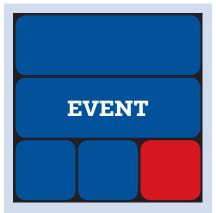


Person - Who am I?

How would you describe yourself in just a few words?

What kind of family are you from? What losses have you experienced? Which people are important to you? What things or activities are important to you?

What is your faith or worldview?



Event - What has happened?

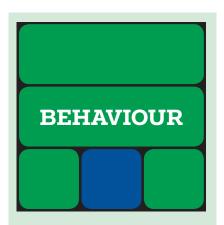
What kind of loss is it?
How much of the event did you witness?

How did it affect you? What has changed for you? What questions do you have?



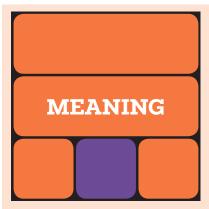
Feelings - What do I feel?

Which feelings do you have: anger, fear, sadness, happiness or other? How do you express your feelings?



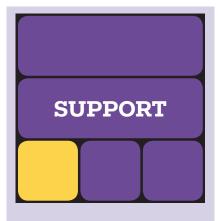
Behaviour - How do I behave?

What has changed in your behaviour? How do you deal with the loss?



Meaning – What does this mean for me?

What will you lack?
What does the loss mean to you?



Support – What do I need?

Who can you turn to?
How do you communicate (spoken language, sign language, pictograms, photos, other...)?
What would help you understand what happened?

What might help you express your feelings?

What activity might help you? What are the things that make your life valuable?



Give brief answers to the following questions. Skip the question when you don't know the answer.



Person – Who am I?

How would you describe yourself in just a few words?
What kind of family are you from?
What losses have you experienced?
Which people are important to you?
What things or activities are important to you?
What is your faith or worldview?



Event – What has happened?

What kind of loss is it?
How much of the event did
you witness?
How did it affect you?
What has changed for you?
What questions do you have?



Feelings – What do I feel?

Which feelings do you have: anger, fear, sadness, happiness or other? How do you express your feelings?



Behaviour – How do I behave?

What has changed in your behaviour? How do you deal with the loss?



Meaning – What does this mean for me?

What will you lack?
What does the loss mean for you?



Support – What do I need?

Who can you turn to?
How do you communicate (spoken language, sign language, pictograms, photos, other...)?
What would help you understand what happened?
What might help you express your feelings?
What activity might help you?
What are the things that make your life valuable?



Everybody experiences loss in their lives.

Loss can be the result of the death of a loved one, but also of moving house.

Loss can result from group changes or staff who leave the facility.

Or because you grow older and are no longer self-sufficient. Or having the feeling that you are different.

Grief is the term we use for people their react to loss. Grief can feel different to everyone. You may, for instance,

become angry or sad.

The Grief Cube can help people talk about this.

Service users, relatives and staff can all use the Grief Cube.

Together, you can talk and think about what you need.

Each side of the cube represents a question.

You can throw the cube like a dice or discuss the sides one after the other.



Person

Who am I?



Behaviour

How do I behave?



Event

What has happened?



Meaning

What does this mean for me?



Feelings

What do I feel?



Support

What do I need?



Marge is 63-year-old women with a profound intellectual and multiple disability. A few weeks ago, her father suddenly died of a heart attack. She now only has several brothers and sisters left. Joyce has been Marge's personal mentor for a year now and wants to help her deal with the loss. She's had photos of Marge's father printed out and put them up in her room. When Marge's elder sister Jill comes to visit, though, she takes down all the photographs. She says: "Marge has a photo album of her dad in her cupboard and that is enough. Photographs on the wall will only make her upset."

Joyce is angry and annoyed about Jill's attitude and discusses the situation with her coordinator Rachel. Rachel asks Joyce how she is dealing with the loss. Joyce fills in the Grief Cube questions to think this over. She tells Rachel that she had a miscarriage several years ago. That she performed a special ritual to say goodbye to her baby and that this has helped her talk about her loss. Joyce feels it's important that sufficient attention is paid to Marge's loss. She is terribly upset that Marge's sister Jill is making this impossible.

Joyce and Rachel ask clinical psychologist Ruben to discuss Marge's situation in a team meeting. Ruben suggests using the Grief Cube and to also invite Jill. During the meeting, everybody writes down their ideas about each side. Afterward, they take turns throwing the cube. The person who threw the cube, tells the others what they wrote down on that side. Others can react. In summation, the following was discussed:



Person: Jill tells the others a little more about Marge's background. Marge was raised on a farm in a small village. She and her family would attend a Protestant church. They never

talked much about feelings. Her mother died a few years ago. When Jill came to visit, Marge would sometimes grab her hand and point at the cupboard. Marge would then quickly leaf through the album, get tears in her eyes and point upward. Afterward she would snap the book shut as if to say 'enough'. This seemed to be enough for Marge, and that's why Jill feels that now that their father has passed, just occasionally leafing through the photo album will be enough.



Event: When Marge's father recently died, staff took her to the hospital. Her sisters and brothers were there as well. Marge was unusually quiet at the time. Marge also attended the

funeral and placed a flower on the coffin.



Feelings: staff are yet to observe any clear emotion in Marge. They have only noticed that Marge was very quiet when she visited her father in the hospital. After the funeral, she

appears to be exactly the same as before.



Behaviour: There has been no change in Marge's behaviour.



Meaning: Marge's father came to visit her every Thursday afternoon. He would take her to the market to buy some fish. Afterward, Marge would always seem cheerful. Marge

must now do without this weekly event. Jill believes that Marge thinks their mother is 'up there' somewhere. She is not sure whether Marge thinks the same about their father.



Support: During the meeting, Joyce says that when she put up the photographs, she was looking at things too much from her own perspective and that in future she will consult

with the family better. Jill offers to take Marge to the market twice a month on Thursday to buy some fish. Jill is going to ask one of her brothers who lives nearby to take Marge to the market on the other Thursdays. Joyce, Ruben and Jill agree to discuss Marge's situation at the planning meeting to be held in three months' time.



Dagmar is a 33-year-old woman with a moderate intellectual disability. She has been diagnosed with autism. She moved to a care facility almost two years ago. After she moved out, her parental home was sold and her mother moved into an apartment. The transition to a care facility seemed to work out fine during the first 18 months. In the past few months, however, Dagmar has been eating less and regularly experiences mood swings that involve fits of weeping. She can also suddenly become very angry and start throwing things at staff or fellow inmates. This happens primarily just after a relative has been to visit.

Many staff members fear her aggressive behaviour and no longer want to be alone in this group. Relatives of fellow inmates have expressed their concern about the security situation in the group. Dagmar's personal mentor Joe has asked clinical psychologist Hannah whether Dagmar can be prescribed a sedative. Hannah suspects that Dagmar is dealing with grief issues and asks grief and loss counsellor Rita for help. Together with Joe, they use the Grief Cube to think about Dagmar's situation.



Person: Dagmar's file states that she's had a troubled past. Her father was an alcoholic who would sometimes hit his wife and children. He left when Dagmar was eight years old. Dagmar

is a woman of few words, who (apart from her outbursts of anger) seems to be easily satisfied. She can express her will quite well by saying "yes, okay" or "no, I don't want that". She smiles when staff make jokes.



Event: For the first 18 months after she moved to the care facility, Dagmar didn't seem to have any problems with the move. Now she becomes aggressive whenever a relative has

been to visit. Dagmar's mother has told Joe that she has never demonstrated this kind of behaviour before. Grief Counsellor Rita asks if Dagmar has ever been back to her old house after she moved out. Joe says she hasn't. She's also never been to her mother's apartment; her mother always comes to visit her. Hannah wonders out loud whether maybe Dagmar is angry that her family is not taking her home with them when they leave.



Feelings: Dagmar is demonstrating anger, grief and impotence. Hannah believes that Dagmar is possibly suffering from a mood disorder or an unprocessed trauma resulting

from the impact of the events. Rita believes that Dagmar may be suffering from 'stacked loss': her emotions are expressed particularly violently because old losses were never adequately dealt with.



Behaviour: Dagmar doesn't eat well, throws things at people and experiences fits of weeping.



Meaning: Joe, Hannah and Rita believe that the loss of her parental home and old insecurities are having a major impact on Dagmar. Dagmar possibly thinks that her mother is still living in

her parental home but that she is no longer allowed to visit there. This may give her a feeling of impotence and anger towards her family.



Support: Hannah will use diagnostic research to establish whether Dagmar is suffering from a mood disorder or unprocessed trauma. Next, she will determine whether a visit to Dagmar's

GP is required to discuss treatment options. For now, Rita will visit Dagmar every other week. During this counselling trajectory, she will explore whether a visit to Dagmar's parental home and her mother's apartment will help her process the loss. Joe will discuss with the manager how to safeguard the security of the team and Dagmar's fellow inmates. He will propose planning office shifts in such a way that every staff member always has backup available. Joe, Hannah and Rita agree that they will evaluate Dagmar's situation and the situation in the group in two months' time.



APPENDIX 3 EXAMPLES: MUSTAFA

Mustafa is a 24-year-old young man with a mild intellectual disability. He's known exactly what he wants ever since he turned fifteen: to settle down in his own house. Just like his older sisters. When he turned 18, he left his childhood home and went to live in a group home where he receives support and can work towards goals such as doing the laundry, household chores and finding a job. Mustafa is almost always cheerful, except when he has to clean his apartment. Mustafa will say that housekeeping is not 'his thing', and that this time he'll skip it. Sometimes, his mentors will say that if he's so keen on living on his own, he'll have to prove that he can do the cleaning. And then he will do it after all.

One day, Mustafa tells his personal mentor Josephine that he is ready to go live on his own. Josephine tells him she feels differently and gently tells him that he will probably always need support. From that moment on, Mustafa's behaviour changes. He stays in bed and refuses to go to work or do his household chores.

When staff try to make contact with him, he threatens to kick them out if they don't mind their own business. Josephine turns to clinical psychologist Greta for advice. She tells Josephine that what she's told Mustafa might mean the end of Mustafa's dreams for the future.

Josephine and Greta conclude that the communication with Mustafa has been incorrect: he was told that he could work on targets to eventually live on his own, while it is not likely he ever will be able to do so. On the other hand, they also wonder whether there are aspects of Mustafa's dreams for the future that could become reality after all. They agree that Josephine will use the Grief Cube to talk to Mustafa. Mustafa gets up out of bed because he's curious about the Cube. In addition to the Grief Cube, Josephine has also brought a set of pictograms that she spreads out on Mustafa's table. She tells Mustafa he can choose a pictogram for each side of the Cube.



Person: Josephine asks him who Mustafa is and which pictogram would be the right one. Mustafa comes from a loving family. He is a Muslim, and in his culture family is very impor-

tant. He picks a pictogram representing a family and puts it in the holder on the 'person' side of the cube.



Event: Josephine asks Mustafa how he felt when she said that he wouldn't be able to live on his own?' Mustafa says that he wanted to hit her. They select a pictogram showing a

person hitting another and Mustafa puts it on the 'event' side of the Cube.



Feelings: Josephine asks how that makes him feel and lays down several pictograms of emotions. Mustafa picks up a pictogram with an angry face and puts it on the 'feelings' side of

the Cube'.



Behaviour: Josephine asks Mustafa what he does when he feels that way. Mustafa picks up a pictogram of a person who is asleep, because recently he has kept to his bed most of the

time. He puts this on the 'behaviour' side of the cube.



Meaning: Josephine asks what Mustafa lacks. Mustafa chooses a pictogram of a house. He puts it on the 'meaning' side of the cube. Josephine asks him to tell her more, what his

dream house would look like Mustafa tells her that he would have his own doorbell and a doormat with 'Welcome' on it, just the one his sister Yasmin has, that he would have a cat flap because he wants a cat and would hire a cleaner and buy a dishwasher. He would buy a DVD player and lots of DVDs just like his brother in law. And that he wants a vegetable garden and learn how to cook so his family can come to dinner, and that when he lives on his own, he could finally go look for a girlfriend.



Support: Josephine says that the mentors did not explain things to him correctly and that she is sorry that it affected him so strongly. And that staff do in fact believe that Mustafa

will always need some help from others. But that she also believes that some things from his dream for the future could actually be realized. Mustafa's face lights up when she says that. She suggests discussing this with his family and her colleagues. They agree to discuss this further during their next appointment. Together, they choose a pictogram showing people sitting round a table and put it on the 'support' side of the cube.



WOULD YOU LIKE TO LEARN MORE?

The Loss and Grief Team can be reached via: rouwenverlies@amerpoort.nl

We would love to receive your suggestions for changes or improvements to the Grief Cube. Your comments allow us to further develop the Grief Cube.

The Grief Cube was developed by the Amerpoort Centre of Expertise in collaboration with Sherpa (care facility) and the Radboud University Medical Centre.

Photography: Ineke Oostveen

