This is a draft version of the workbook and is subject to further change. Please do not circulate beyond your team.

HospiceUK

Compassionate Employers

CHAPTER 3- Professional grief

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Contents

Introduction

This is a draft version of the workbook and is subject to further change.

Please do not circulate beyond your team.

Disclaimer

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Who is this workbook for?

This workbook is a reflective learning resource for frontline staff whose work may bring them into contact with grief, caring responsibilities, emotional labour, distress, death, dying or bereavement.

It is designed to support individual reflection and team conversation.

It should be used alongside, not instead of, appropriate management support, supervision, occupational health, Employee Assistance Programme, HR guidance and organisational wellbeing provision.

How to use this workbook

This resource is for reflection and learning. It is not a substitute for clinical, psychological, occupational health, HR or emergency support.

Each chapter can be used as a standalone resource, however, the proposed order of chapters is:

- Compassion fatigue and compassion satisfaction
- Burnout
- Professional grief
- Stress and resilience.

Throughout each chapter there are opportunities for individual reflection and group reflection. Below is some guidance on how these activities should be facilitated:

Individual reflection guidance

- You do not need to answer any questions that feel too personal, unsafe or difficult.
- Pause at any point.
- If this content brings up distress, speak to someone you trust and access your organisation's support routes, such as your manager, supervision, occupational health, Employee Assistance Programme, HR, GP or urgent support if needed.

Group reflection guidance

- Participation is voluntary.
- No one should be expected to disclose personal trauma, bereavement, mental health experiences or private circumstances.
- Confidentiality expectations should be agreed at the start.
- Managers should not use reflective worksheets as performance management evidence.
- Teams should agree what can remain within the group and what may need to be escalated for safety or support.
- A facilitator is identified for more sensitive discussions, especially professional grief and burnout.

Our wider workplace

- Looking after ourselves matters, but wellbeing is not only an individual responsibility.
- Our workplace plays a large role in supporting our wellbeing.
- Workload, staffing, supervision, leadership, culture, psychological safety, fairness and access to support all shape whether people can stay well at work.
- *To access your organisation's support, please contact someone in your organisation for more information - such as your manager or HR team.*

About Compassionate Employers

The Compassionate Employers Programme launched in 2019 to provide organisations with the skills, knowledge, and resources needed to effectively support employees and customers through terminal illness, caring responsibilities, and bereavement.

We envision a world where all employers are equipped to advocate for and support employees and customers through significant life moments. Our programme is built around three key pillars: greater visibility, education, and connection.

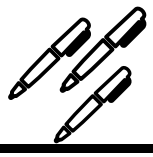
If you would like more information about Compassionate Employers, we would love to invite you to book a meeting with our team here: Compassionate Employers Intro Chat

About Hospice UK

Hospice care eases the physical and emotional pain of death and dying. Letting people focus on living, right until the end. But too many people miss out on this essential care. Hospice UK fights for hospice care for all who need it, for now and forever.

Membership of Hospice UK is open to UK organisations that provide hospice care. Anyone who works or volunteers for a Hospice UK member organisation can access our member-only services and resources. For more information on how to make the most of your Hospice UK membership, see: https://www.hospiceuk.org/innovation-hub/membership

Workbook key

	**Lightbulb moment**: An interesting fact or extra information.
	**Individual reflection**: An activity for you to complete (participation is optional).
	**Group reflection:** An activity to do with your team (participation is optional).
	**Important note!:** Information which is important to note.
	**See Glossary**: Detailed definitions.
	**Tool**: You can use this reflection/information outside of the workbook.
	**Quote/quotation**: Relevant quote/quotation.
	**Key term**: Important definition.
	**Reminder to be kind to yourself:** This activity may feel challenging or emotional (participation is optional). Please do take care of yourself and take breaks as needed.

Professional grief

'We burn out not because we don't care but because we don't grieve. We burn out because we have allowed our hearts to become so filled with loss that we have no room left to care'

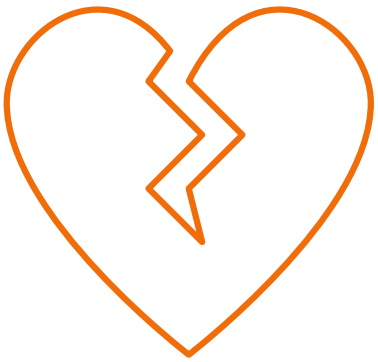
Rachel Naomi Remen[1]

Why this matters

Grieving is something we, as a society, can find very difficult to talk about.

Even in hospice settings where we play foundational roles in caring for dying and bereaved people, the grief we may experience as a result of our working and volunteer roles (professional grief) can feel like it is hidden in the shadows.

When we don't acknowledge its impact we can feel alone at a time when we need connection.



What we will cover

In this chapter we look to understand what grief can look like and the ways we can experience grief as a result of our professional roles. We will cover:

Important note! If this content brings up distress, speak to someone you trust and access your organisation's support routes or urgent support if needed.

Definition: what is grief?

Grief is an incredibly personal experience and there is 'no one right or universal way to experience or respond to loss'[2].

There are many terms that are used to describe and discuss the experience and process of loss*. For the purposes of this workbook, we will be using the following definition, however, terms can feel limiting. Please use whatever language makes you feel comfortable.

Key term

Grief is the emotional response to a significant loss or anticipated loss, whether through death or through living losses.

It is a universal human experience[3] and it is described by O'Connor[4] as an often painful emotional state that repeatedly rises and fades.

Individual reflection: What other words come to mind when you hear the word 'grief'?

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In hospice settings, we are often supporting others in their grief. We can also experience grief ourselves as a result of our work or volunteer roles. This is called *professional grief.

Before we explore professional grief, we will first look at the impact of grief.

See Glossary for further definitions relating to grief including professional grief.

Impact of grief

Grief can have a huge effect on our minds and our bodies. It can affect every area of our lives, some of which are listed below. It is important to recognise that no two experiences of grief will feel the same and that some of these symptoms may come and go.

Cognitive

- Difficulties in concentrating and processing information
- Difficulty making decisions
- Forgetfulness and 'brain fog'
- Confusion

Behavioural

- Withdrawing from social interaction
- Irritability
- Searching/yearning

Physical

- Difficulties sleeping
- Tiredness/exhaustion
- Weight loss or gain
- Losing appetite
- Stomach issues
- Dry mouth
- Aches and pains
- Headaches
- Feeling as though there is a weight on your chest/chest tightness
- Physically run down
- Increased blood pressure[4]

Emotional

- Sadness
- Fear and anxiety
- Numbness
- Loneliness
- Helplessness and guilt
- Anger at the person or at the world
- Worried about mortality
- Shock – even if death isn't sudden the finality of death can feel shocking
- People may feel acceptance or relief. For many who are living with ***anticipatory grief**, there can be a huge sense of relief knowing that they don't have to suffer anymore and knowing that you don't have to worry about them.

Spiritual

- Grief can really challenge someone's faith; it can make them question the meaning of life or their belief systems
- Grief can inspire someone to lean more heavily into their faith, becoming more active within their faith community or changing their practices for worship

See glossary for definition of *anticipatory grief.

Symptoms identified in NHS[5], NHS inform[6], Gilewski[7]

Models of grief

There are different models of grief which try to explain a complex and deeply personal process.

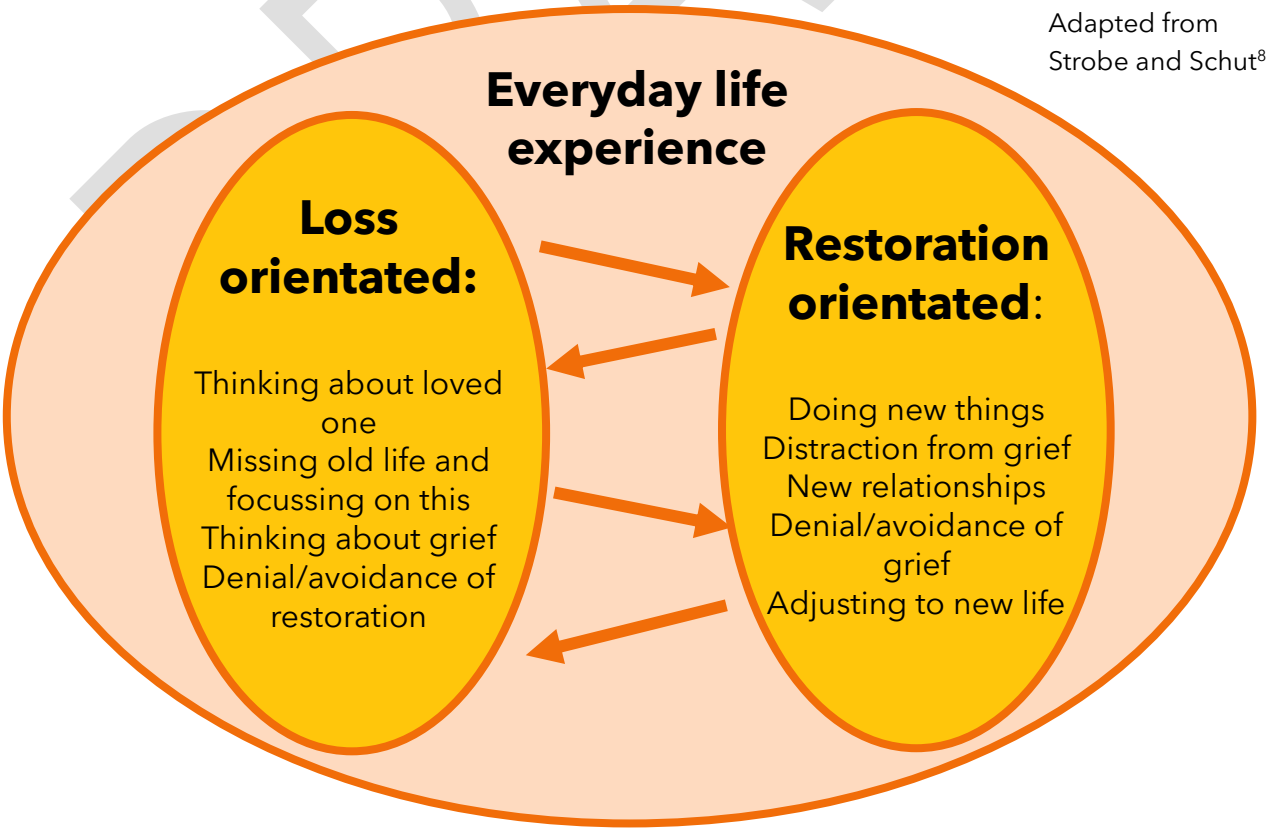
While they may not be relevant to everyone, models can help some of us feel less alone in the symptoms we are experiencing.

1. 'The Dual Process Model of Coping with Bereavement'- *Strobe and Schut (1999)*[8]

The Dual Process model of grief, instead of progressing through stages, suggests that grief oscillates between loss days and restoration days as depicted in the diagram below.

We may move between these two states many times even on the same day.

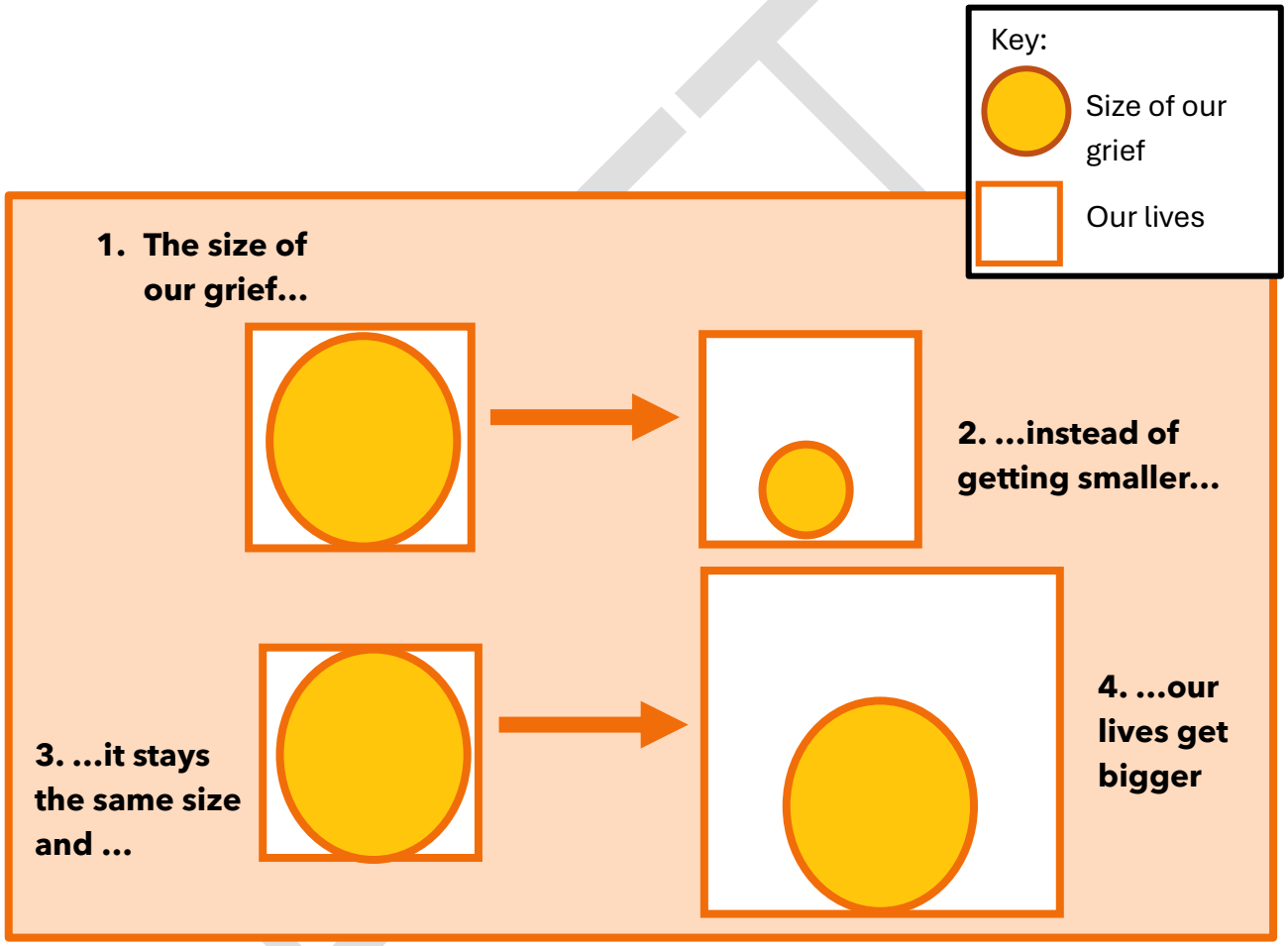
Adapted from Strobe and Schut[8]



2. 'Growing around grief'- *Tonkin (1996)*[9]

The 'Growing around grief' model suggests that grief doesn't diminish, but our lives expand around it.

There are moments when our grief feels as intense as the day of the loss, yet there are also times when life is lived in the space outside the circle of grief.



Adapted from Tonkin 1996[9]

Around significant dates our grief can feel incredibly intense, as if we have no capacity for anything else in life.

However, it is a reminder that life can and will continue to grow around our grief as we learn to live alongside it.

Pause and reflect

Grief models can be helpful for some but oversimplifying for others. What are your thoughts?

Be kind to yourself. Thinking about grief can bring up many different thoughts and feelings – pause or skip this question if you want to.

Individual reflection: Has grief impacted you? If so, what symptoms have you noticed?

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Important note! If this content brings up distress, speak to someone you trust and access your organisation's support routes, such as your manager, supervision, occupational health, Employee Assistance Programme, HR, GP or urgent support if needed.

Grief and the brain

Another way of understanding grief is through the lens of neuroscience.

When we were researching this workbook, we came across O'Connor's book, 'The Grieving Brain' [10]. For some, neuroscience may bring clarity while for others it can feel too clinical so please take care of yourself in this section.

These were the questions we were asking:

Question: How does the brain process the world around us?

Answer:

Our brains process multiple streams of information, encoding the world around us. Using external data, it creates **internal maps** of our relationships and surroundings.

Specific neurons fire encoding locations of particular information, e.g. we unconsciously know the location of the armchair in the living room and can picture where our child is at 1pm on a Monday (lunch break at school).

These internal maps support us in predicting and managing our day-to-day.

Question: What happens to the internal map when someone dies?

Answer:

When someone close to us dies, while we may consciously know that they are no longer in the 'physical world, our neurons fire every time we expect our loved one to be in the room'[10].

Our brain hasn't updated the internal map. Each time this occurs, our virtual map with that person in it conflicts with the external world and reality that they are no longer here. In this moment we feel the pain of grief.

Question: How does our brain cope with loss?

Answer:

O'Connor[8] suggests that for our brain, grieving is a form of learning, updating the map and 'integrating the loss into our lives'.

It takes time for our brains to process that the person is no longer here. Our brains struggle to predict what a life without them looks like. 'Updating the map' is a process that can be deeply painful, especially if we were very close to them.

Question: What does this mean for me?

Answer:

'Integrating loss' sounds like a detached and practical process, however, we know that this is not how we experience grief. Grief continues throughout our lives, and we feel it at each point when overlap occurs between our virtual map and our current reality.

However, as we continue to live, these feelings of grief become familiar; we find ways of coping and including the love we had and continue to have, into our lives.

Lightbulb moment: For some further reading on how grief affects the brain, see: O'Connor M-F. The grieving brain: the surprising science of how we learn from love and loss. New York: HarperOne; 2022.

Professional grief

Key term

Professional grief is the type of grief experienced by individuals as part of the work they do[11] (e.g. death of a patient/individual).

It 'differs from personal grief as it is anticipated daily, and a result of the job chosen' [11].

In both clinical and non-clinical hospice roles we build caring relationships with people in times of pain and suffering[12]. We care deeply and care is foundational in our work[12]. It is understandable that we may be impacted by grief, death and dying.

Professional grief can feel different to our other experiences of grief. It can be complex and multifaceted for several reasons:

Repeated exposure

to death and dying as part of our roles

Professional responsibilities

and upholding professional expectations whilst managing our grief

Our relationships

with the individuals we work with vary and may differ from our colleagues'. We may be particularly impacted by a death if:

- we had a close professional relationship
- we are reminded of personal experiences of grief
- we felt unable to offer the care we wanted to

'Part of the job' mentality

resulting in stigma around professionals expressing grief[5]

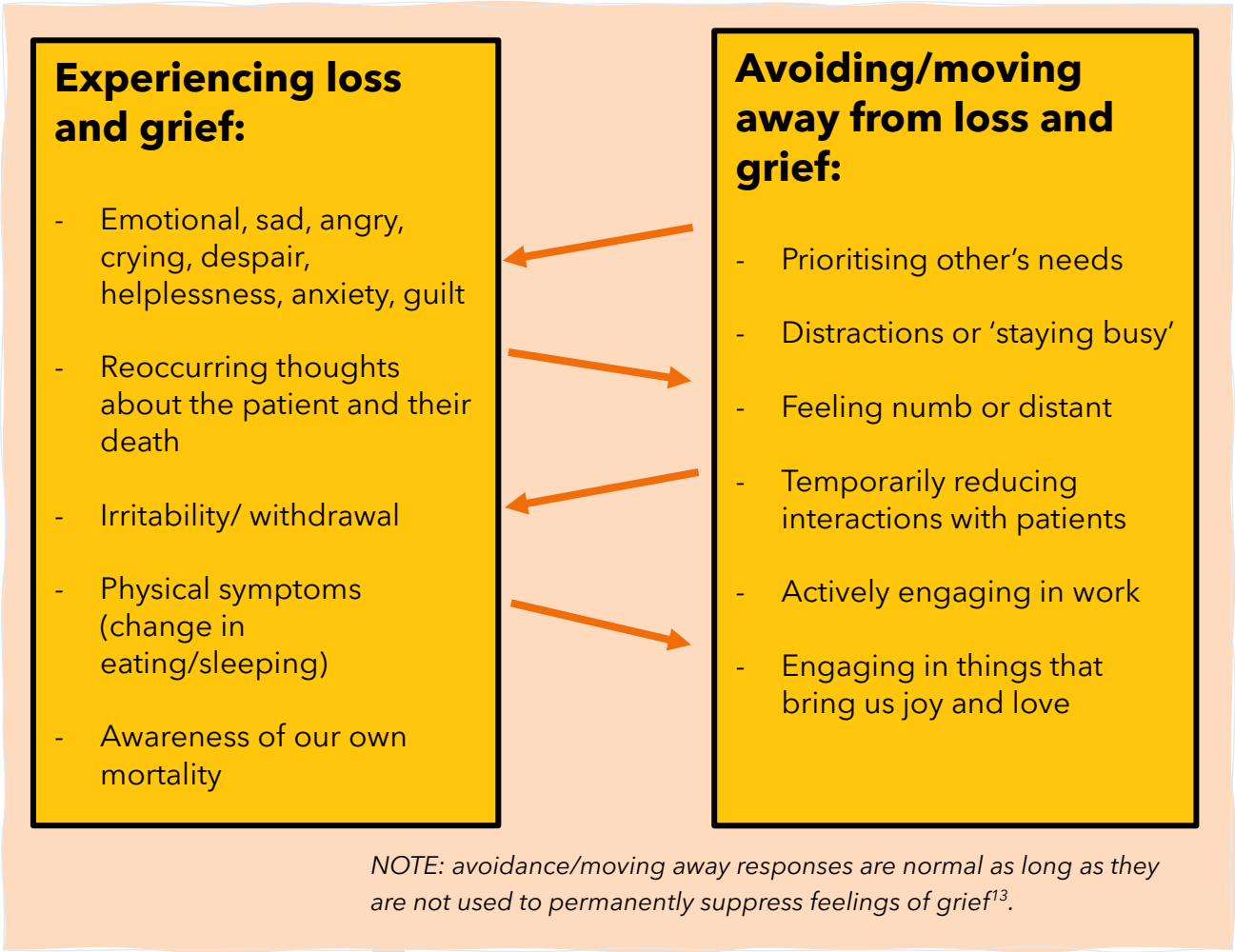
Identified in Phillips, Trainum, Thomas Hebdon[11] and Papatatou[13]

Be kind to yourself. Not all deaths may affect us in the same way and that is OK. We shouldn't shame or blame ourselves if we feel things differently to our colleagues or respond in a different way to previous deaths.

Professional grief: Papadatou's model

Incorporating the differences of professional grief, Papadatou developed a model of professional grief which draws on the Dual Process Model[8] and includes the cumulative effect of experiencing multiple deaths.

Adapted from Papadatou[14]



NOTE: avoidance/moving away responses are normal as long as they are not used to permanently suppress feelings of grief[13].

Papadatou[13] argues that professional grief occurs as an **ongoing fluctuation** between **experiencing the grief** and loss experience and by **moving away from the loss** experience.

Lightbulb moment: This fluctuation from one to the other is necessary, adaptive, and healthy.

When we are not able to fluctuate, we can become totally overwhelmed or completely repress our grief[15], increasing risk of compassion fatigue and burnout[11].

Practical tool: Supporting ourselves

Professional grief can be really challenging to cope with. Due to our roles, boundaries and confidentiality we may or may not have access to the rituals or support we would have in personal bereavements, e.g. attending the funeral or getting support from those close to the person.

Therefore, as individuals and as teams we need ways that allow us to experience and fluctuate in our grief in a supported and sustainable way.

Individual reflection: Give examples of ways/activities in which we as individuals can fluctuate in our professional grief.

Experiencing loss and grief:

- *E.g. reflecting with colleagues, feeling sad*
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- .....
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Avoiding/moving away from loss and grief:

- E.g. laughing with friends, watching a movie
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Titles adapted from Papadatou[14]

Important note! If this content brings up distress, speak to someone you trust and access your organisation's support routes, such as your manager, supervision, occupational health, Employee Assistance Programme, HR, GP or urgent support if needed.

Supporting our teams

What can often make our experience of professional grief so challenging is the ways in which it has often been sidelined[13], disenfranchised, 'hidden in private shadows and not openly expressed'[11].

Therefore, we need to find support that meets the needs of our teams, that allows us to be open about professional grief and to experience and process it safely.

Individual reflection:

1. How do we currently support each other after a death?
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2. How are deaths acknowledged for staff at our hospice?
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3. What helps us feel safe to talk about grief?
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4. How are non-clinical colleagues and volunteers supported?
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5. What could we do differently as a team?
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   .....

Tool: If it feels safe for you to do so, the following five reflections can be discussed as a team. You can further share them with your

Worksheet: team conversation

Supporting our team

Professional grief is something that is not often discussed and for our teams it can feel sidelined[13], 'hidden in private shadows and not openly expressed'[11].

The need to better support our teams through professional grief and social support has been identified as significant in supporting our team's wellbeing and mitigating burnout[11].

Further, Papadatou[13] argues that there are three distinct ways in which we and our organisation can support our teams who regularly encounter death and dying as part of their role:

- Holding environment
- Collaboration and open teamwork
- Commitment.[13]

Important note!

Group reflection guidance

To facilitate this activity safely ensure that:

- Participation is voluntary.
- No one should be expected to disclose personal trauma, bereavement, mental health experiences or private circumstances.
- Confidentiality expectations are agreed at the start.
- Managers do not use reflective worksheets as performance management evidence.
- Teams agree what can remain within the group and what may need to be escalated for safety or support.
- A facilitator is identified for more sensitive discussions.

Group reflection: As a team how can we support each of the three factors detailed below?

1.Holding environment

How can we support safety, order and predictability when encountering death and dying at work?

E.g. timely emotional support

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2. Collaboration and open teamwork

How can we improve inter-team and interdisciplinary collaboration?

E.g. meeting with other relevant services

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Our team

3. Commitment

How can we commit to the requirements of our individual roles and to commit to support each other?

E.g. clearly defined responsibilities

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Adapted from Papadatou[13]

Worksheet: individual reflection

Professional grief self-care plan

How we experience professional grief varies from person to person. Certain losses may impact us more than others for a variety of reasons and we can find it challenging to cope with.

When we are struggling, it can be hard to know what helps, who to turn to, or what support is available. By creating a self-care plan, we can identify ways in which we can look after ourselves as we experience and fluctuate in our professional grief.

Important note!

Individual reflection guidance

- You do not need to answer any questions that feel too personal, unsafe or difficult.
- Pause at any point.
- If this content brings up distress, speak to someone you trust and access your organisation's support routes, such as your manager, supervision, occupational health, Employee Assistance Programme, HR, GP or urgent support if needed.

Be kind to yourself. These are some ideas of things you to reflect on. Take your time answering the questions.

Individual reflection: Give examples of what can help in each category.

Connection and support

- Who can I turn to when I am struggling? Who can support me (professionals or loved ones)?

.....

- Who can I speak to at work? Who can support me in my team/organisation?

.....

Emotional

- How can I experience and process the feelings I am having? *For example, mindfulness, reflections, self-compassion.*

.....

- How can I allow myself to move away from the experience of grief and loss? What makes me feel good?

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Physical

- Grief can have a significant physical effect on the body[8]. How can I look after my physical health? *For example, sleeping, eating, drinking water, and movement.*

.....

Practical

- What situations might I encounter at work that may bring up feelings of professional grief? *(For example, communicating with the bereaved family).* What support is available?

.....

Headings adapted from South West Yorkshire partnership NHS Foundation Trust[16]

Glossary

The following quotation is a helpful way of understanding grief in relation to burnout, compassion fatigue and vicarious traumatisation:

'Dying or bereaved people do not cause our burnout, compassion fatigue or vicarious traumatisation. It is not something they do to us. […it is] as a result of our relationships with them, ourselves, our coworkers, and work context which is perceived as unsafe or uncaring' **Papadatou[13]**

Below are some further clarifications which may be of help:

- **Grief** is the emotional response to a significant loss or anticipated loss, whether through death or through living losses. It is a universal human experience[3] and it is described by O'Connor[4] as an often-painful emotional state that repeatedly rises and fades.

- **Professional grief** is the type of grief experienced by individuals as part of the work they do[11] . This could include the death of a patient or someone with whom you have built strong professional relationships.

- **Bereavement** is experienced because of the death of someone important to us. Societally there are processes, expectations and rituals which culturally signify bereavement[3].

- **Disenfranchised grief** is a type of grief that is often misunderstood, un-acknowledged, unexpressed, undervalued, or invalidated by others or social norms. Disenfranchised grief can feel similar to grief through bereavement and is experienced by the individual as a significant loss while not being granted the space to grieve.

  Some examples may include breakdown of relationships, estranged friendships, loss of job, loss of prior abilities, relocation or stigmatised deaths[17]. *It was first coined in 1987 by Ken Doka*[18].

- **Anticipatory grief** refers to feelings of grief or loss that you may feel before the loss happens. For example, this could include feelings of grief for a loved one living with a life-limiting condition.

Rando[19] further includes in anticipatory mourning not only the grief of the expected death but further grieving the lost experiences and hoped for future.

- **Mourning** while often used interchangeably with grief, mourning has been defined as personal and public expression of grief.

  Brabant[20] suggests that mourning encompasses social expectations of what grief should look like and cultural definitions of how we should grieve that loss.

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