

The Impact of Grief on the Carer

Notes from Sanctuary meeting 8 June 2021 - based on a presentation by JOY ANASTA

Grief

We often think about grief in situations, eg when someone dies, but grief occurs whenever something changes in our lives. Even positive changes bring some grief as there is always some loss.

In the carer experience, grief is often what we would call ambiguous – it's hard sometimes to put a finger on what we've lost and what we're grieving.

Ambiguous Grief

Ambiguous loss and grief is when we have a person that is no longer the person we once believed we were in relationship with... When we look at that young adult and wonder what happened to that little person who happily went off to school and play with friends... where did that all go? Or when we look at the partner who has descended into drug use or alcohol in order to try and manage life, but as a consequence asks us to live an intolerable reality. What is reasonable?

Very few new parents are thinking about BPD when their baby is born. When partners, parents and siblings enter into the relationship or make a commitment to a person, we rarely consider that one day, we might become their carer.

It can almost be a physical jolt of shock when we realise that our new normal is to be a carer, and that might continue for a long time (maybe a lifetime). It is difficult to get our head around what it means to be a long-term carer. Lots of emotions, and importantly, there is lots of ambiguity. Exactly what will our caring role be? Will our loved one recover? How long will it take? This ambiguity leads to a specific type of grief, known as '*Ambiguous Grief*'

[Ed: From Wikipedia: '*Ambiguous loss* is a loss that occurs *without closure or clear understanding*. This kind of loss leaves a person searching for answers, and thus complicates and delays the process of grieving, and often results in unresolved grief... Experiencing an ambiguous loss can lead to personal questions, such as, "Am I still married to my missing spouse?" or "Am I still a child to a parent who no longer remembers me?". Since the grief process in an ambiguous loss is halted, *it is harder to cope or move on* to acceptance from the type of loss experienced']

What holds the carer in this ambiguous grief?

Often our guilt, shame, blame and fear.

Carers often have the expectation that '*If I am available enough, patient enough, for long enough, things will change.*'

When we stay in ambiguous grief for a long time, we can experience chronic grief (more than 3-6 months duration.)

There are two kinds of *Ambiguous Loss*:

- Physical Loss: When we experience loss of emotional connection due to a physical loss (eg a missing person)

- Loss of Psychological Mind: When they are physically present, but they've emotionally changed in their relationship with us – we miss the way the relationship used to be (eg dementia)

Carers can experience *Ambiguous Loss* when they feel the loss of safety, certainty and security.

When we are together and I am able to trust who I am and who you are, it can be a safe place. Not necessarily conflict-free, but a safe place. Healthy conflict is when each person is able to take responsibility for, and regulate themselves.

In people with BPD, this ability to regulate and navigate their emotional responses is challenged.

Carers are often uncertain. What we may be able to say safely one day, we may not be able to say the next day. Perhaps nobody puts the signs up to tell us that, or pre-warns us when today is not a good day. It's unclear where we stand. This is an *Ambiguous Loss*.

We start reading the little nuances. "Am I safe? What did that flicker of your eye mean, what did it mean when you moved your head that way, how am I able to approach you and be safe?" Carers can become profoundly exhausted by this hyper-alertness and hyper-vigilance. This is a consequence of the *Ambiguous Loss*.

Another kind of Ambiguous Loss

Sometimes we may love the person for whom we care, but we may not like them. We may then also be challenged in liking ourselves in our caring role. We may be uncertain about what our relationship was and what it has become. Often, we are grieving the loss of our own relationship with ourselves.

When working with a diagnosis (like BPD) or questioning what's happening, we believe we can get through. "*I love you enough to get through*" or "*We can do this together.*"

Our grief and resultant ability to manage changes are impacted when we are tired, hungry, lonely, hurt etc. Am I:

- H – Hungry?
- A – Angry?
- L – Lonely?
- T – Tired?

These are warning signs! If I am unable to regulate myself, my human response is to be reactionary – which can lead to poor behaviour and then we experience guilt, blame and shame.

As a motivator, guilt is extremely powerful. If you believe you are guilty, you will provide leverage that the other person could use against you (not from malicious intent but because the focus of the person living with BPD is that everything filters through "how I feel about what just happened". "I will filter everything through how that impacted me so if I can blame, shame or guilt you so that I can feel better, I will do it")

This guilt is a human survival mechanism that has lost its boundaries. The more you believe your guilt, the more available it is, to be weaponised against you.

Carers look at their loved ones and say, "*Their life is terrible.*" Is it true that it is terrible, or is it just different?

Are you a failure if you don't get it right all the time? Carers motivated by guilt can end up carrying the bulk of the responsibility.

Parents are dictated by the desire to be the best we can be. We can take on grief as a motivator, driving us to seek a change in our situation, because to grieve without ending feels intolerable. Guilt and worry give us something to think about when we don't know what to do. To do nothing would be intolerable so we have another conversation, we look for another mental health professional, we try different medication... We try and try and try. Trust in your parenting! Joy does not suggest we do nothing; just to consider what is reasonable.

Joy also suggests that it is possible some carers may have broken their own backs trying to carry more than is a reasonable load. It's likely that everyone in the room and on-line has tolerated and found a way to navigate behaviours in their homes that you may not tolerate from anybody else. Permission was given and that permission was noted by your loved one. So when we start to seek to change things it gets uncomfortable and like a rubber band stretched to its full capacity it's easier for us to spring back to what it has always been than to stay stretched.

Guilt and grief will drive us. Guilt asks us to be the problem. Fear will silence us – we would rather tolerate than speak out.

The challenge is to step out from under the fear, to speak to grief, blame and shame – ask “*what is my responsibility here and how do I intend to move forward*” - realise when to continue as we were, does not serve the other person well.

When you live an intolerable reality. Ask what is reasonable. It is not reasonable to ask ourselves to be poorly treated or unkindly dealt with.

Boundaries

We need to be aware of our own boundaries and choose what is reasonable.

Write down the things that are causing you grief, observe your limits, then decide where reasonable boundaries can be implemented.

When you establish a boundary, your loved one's first reaction may be escalation of poor behaviour as they test the boundary. If you are clear and consistent, i.e., if you persist and make clear definitive responses, there will ultimately be behaviour change in your loved one.

What if the escalation is very severe? Establishing a boundary does involve some risk – but any change to your usual behaviour involves risk.

Having BPD does not remove the responsibility for one's own behaviour. Your loved one may have some ability to regulate – if the boundaries are reasonable, look for examples that prove this. Maybe they can go to work and function well, maybe they happily unpacked the dishwasher when Dad asked. Look for occasions when they did regulate themselves and see that they *can* do it.

[Ed: The *Family Connections* course includes a critical skill – how to observe and communicate a boundary in a non-confrontational manner]

Questions from carers

1. **Q: What about suicide?**

A: A carer said to her son *"I can't do this anymore. The fear leaves me drained. If you choose to take your life it will be your choice and I won't take responsibility for it."*

She made it clear that she was not responsible for the choices he made about his life. She gave her son love and dignity. She told herself *"I too am a valuable, valued person."* She made it clear that she would not accommodate threatening behaviour and behaviour that she would not tolerate from anyone else.

The reality is that *You* cannot keep anyone alive. It is scary, but no amount of begging will make a difference if they are determined to do it.

2. **Q: How do I live with this grief that never goes away?**

A: Sometimes you just have to make friends with it. Find a way to navigate the grief.

William Warden wrote books about grief.

"I am uncomfortable, but I have a choice." We all have choice. Who you choose to be in your caring role is your choice. *"That I choose to be in this role is an empowerment. I will choose who I am in this relationship."*

Suggestion – write down *Grief* and what it means. Many losses are intangible. *Who do I want to be?* Put parameters around it. You choose yourself in this role. Be unapologetic for the choices you make.

3. **Q: I am wondering how to reach my son when he goes on a rant about his parents.**

A: The person with BPD will freely give responsibility to you.

Some people with BPD will react differently to different people eg have a fixated response to one, and a benign response to the other.

It is a lie that you have ruined their life.

If they rant, leave them to it. It may be their truth, but it doesn't have to be yours. They will fixate on their truth, no point in arguing.

[Ed: Family Connections program would suggest validating their emotion here, while acknowledging that you do not have to agree with content of the statement.]

If your own safety is an issue, leave the premises or call the police.

4. **Q: Does age make a difference to how you respond?**

A: At 16, they are still trying to understand, navigate confusion.

Don't have a conversation when they are in a heightened state. Say *"we can have a conversation if you want but if we can't now, we can come back later."*

5. **Q: More about Boundaries... examples.**

A: A basic boundary is to keep yourself safe, regardless of where you are in your journey.
"I always will keep myself safe"

Boundaries can be emotional, physical, spiritual. They protect me from you, and you from me.

"I'm going to love you enough to say this is not a conversation we will have now."

Put the boundaries in place when things are calm. Write them down clearly, consider making a contractual agreement that you both sign.

Townsend and Cloud write well about boundaries.

The book 'Don't feed the ducks' by John Raven. When you take bread to the duck pond, then you see the sign saying 'don't feed the ducks, bread is bad for them', but the ducks are carrying on because they want the bread. What will you do? If you feed them or you don't feed them, either way you feel you are doing a terrible thing. What should the boundary be?

6. **Q: What if things are rarely calm?**

A: Perhaps consider whether they need to live with you.

[Ed: If things are rarely calm, we suggest the course *Family Connections* to learn skills to soothe and calm emotional dysregulation]

7. **Q: Concerned about 3.5yo granddaughter. Mother who has BPD won't let us near her. We can't get near her to set boundaries.**

A: Tension in relationships leads to resentment. Whenever one parent is played against the other, *get professional help* eg counselling.

Regulation is possible. It is not your responsibility to navigate your daughter's relationship with her child. Notify your daughter's psychologist/psychiatrist if you have concerns – they are mandated reporters to government agencies. Be prepared for the possibility that the court may give custody of the child to you.

If your daughter does not trust you, the welfare of her child is an imperative.

8. **Q: How to navigate feelings of guilt, particularly when there are children involved?**

A: No piece of DNA implies you have responsibility over another person. If you act out of obligation, you're available to the guilt. This will do you more harm than good.

Sometimes we accept responsibility that is given to us eg young children are sometimes taught to take responsibility for others.

9. **Q: What is the difference between guilt and love?**

A: As carers we love because we demonstrate something. We don't always feel loving. You may be in an 'obligationship'.

Love = a discipline, not an emotion. *"I choose to be in this place"*. It may mean that I say No when things go too far.

Guilt = becomes confused with love when it motivates us to stay where we are. It is where you accept responsibility – can keep you in a place for the wrong reason.

10. **Q: Our son is adopted – could this have played a part in his BPD eg feelings of rejection.**

A: Biological involvement plays a part in all sorts of things – we don't know his genetic influences.

Be careful not to go down a rabbit hole here – adopted or not he can choose how to respond – go into abandonment or practise gratitude for all he has.

11. **Q: What are some techniques to help my partner and me get calm after we have had an argument?**

A:

- Breathing – when we are heightened every organ in our body becomes hyper adrenalized. When under threat we are hyper-aroused. Deliberately moderate your breathing – hand on solar plexus and feel your hand moving up and down with your breath – do it until you are calm.
- Put both feet on the ground. Feel the ground, feel your toes. Feel the strong dependable ground, always there to support you. Remind yourself that you are safe. Stay in your body until you are regulated again.

[Ed: as Joy described each exercise, Joy slowed her voice and lowered its pitch, and I noticed the calming effect this had on me, while I listened to her voice]

Practise these calming techniques when calm. In the heat of the moment, it can be difficult to remember how to do these things, but the more you practice, the easier it will be

12. **Q: Our son talks about attachment – multiple phone calls & messages, a 90-minute text thread and a one hour visit with him in the last 24 hours. He says we have caused all his problems.**

A: You are doing all the work. Don't have long SMSs and conversations. If you've been talking for a long time about it, you have lost the battle. You are running down a rabbit hole that is going to end badly.

Say *"I love you. We'll stop this conversation now because it will end badly. I will talk to you when you are calm."* or *"I love you enough to stop this conversation now."* *"If you choose to ring back my phone will be off"* Disengage.

13. **Q: What are some strategies to break the cycle of blame? One person with BPD has a note on her fridge which says: "I am not to blame for my BPD condition, but I am responsible for getting better."**

A: Don't engage! When a problem emerges, stop in now. The minute you try to justify or legitimise, you've lost.

You can say *"I don't believe that to be true, but if you choose to believe that, I will leave it with you."*
They will escalate to try to keep you in the position but do not engage.

"If you will not regulate, I will regulate myself."

14. Q: Other examples of boundaries?

A: Two books – *"Boundaries"* by Townsend and Cloud – and *"Don't feed the ducks"*.

Don't make boundaries harder than it is. *"It is my responsibility to keep myself safe."* *"It is my responsibility to regulate myself."*

Boundaries need to be *clear, firm and unapologetic.*

15. Q: When you enforce boundaries, if you say you'll leave and it gets violent, how do you deal with that?

A: It depends on the person. May be safe to remove yourself, or just walk past them. You may have to lock yourself in a room and call the police.

Police are mandated to respond if you say your life is at risk. If you say you genuinely feel you are at risk and use the words "breach of peace" they have to respond.

Learn to understand the steps – what has led to this escalated step. There will be themes in their escalation that you can learn to recognise. To demonstrate a way to analyse these steps, Joy stood in the middle of the room, briefly described an escalated situation, asked herself what might have triggered it. Then she asked herself what had happened before that while physically taking one step backwards, then she stopped to describe the situation immediately before the escalation and asked herself if she knew what might have been triggering. Then another step back. Then another. Using this analysis, over time, you may be able to find some patterns, and recognise some early triggers and early warning signs of dysregulation.

16. Q: What if your partner undermines you? He doesn't think it is worth enforcing the boundary because of the difficult behaviour (of the person with BPD) .

A: Maybe he feels it is not worth it because there is no hope of change. However, there is no behaviour that is beyond some mechanism of management. How the person with BPD behaves is ultimately their choice.

If you accommodate the behaviour, they'll keep doing it. Nothing makes you being at risk reasonable.

17. Q: I want to hear about hope!

A: The clearer you are about who you are and how you intend to be in the relationship and the boundaries you set, the more hope there is.

A carer shared her story of how her daughter's life changed.

Love is a discipline of boundaries.