

CFU Carers' Support Group



For carers and relatives of people with fronto-temporal dementia and semantic dementia

Newsletter

OCTOBER 2008

Welcome

Welcome to the October edition of our CFU Support Group Newsletter. Thanks to all of you who came to our carers' meeting on 25th September. This was our first talk from Dr Jill Brennan, a Counsellor Consultant from the Clinical Psychology Department at North Manchester General Hospital, who led an interesting and helpful discussion on loss, grief, and mental health. Dr Brennan provided an excellent talk on how to cope with the changes that you face as a carer

and also how to look after yourself and deal with grief in a natural way. As always, we've provided a short summary of the main points of the talk and also some of the discussion points that group members contributed. We hope you find the information useful and if you have any additional comments or questions, try the website, where you can find previous editions of the newsletter, summaries of other talks, and other useful information and links:

www.cerebralfunctionunit.co.uk/carers.html

Loss, Grief, and Mental Health

Dr Jill Brennan, Counsellor Consultant from the Clinical Psychology Department,
North Manchester General Hospital

Introduction

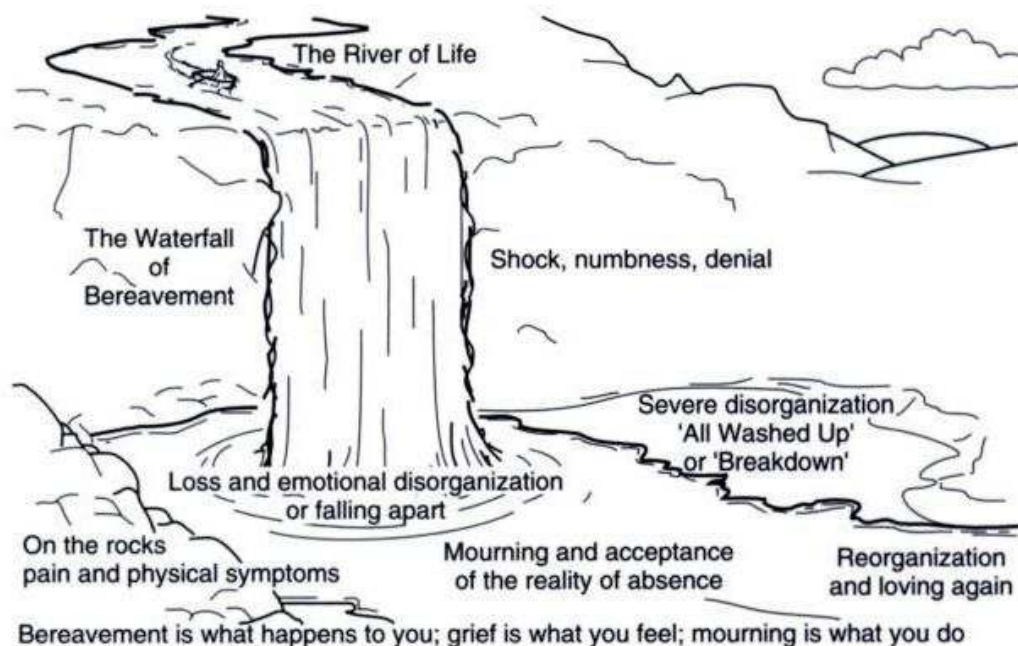
Grief and loss are obviously very relevant issues for carers, and in frontotemporal dementia (FTD) and semantic dementia (SD), where there are profound changes in personality and communication, this is a particularly pertinent topic. Even when the person you care for is physically very well, it might no longer feel like they are 'the person you married' or 'your mum/dad' as their personality might have entirely changed, or they are no longer able to communicate at the same level. It is important to recognise these changes and to be able to cope with them, and in a way, this can be seen as a prolonged 'grieving' process.

What is 'normal' loss/grief?

Grieving is a normal and natural process. It is not necessarily about death, and instead can be about changes of circumstance. So for example, grieving for changes in the person you are caring for would be a natural and normal reaction to the situation you find yourself in. We also grieve for changes in our own lives, so for example, if you had to give up your job to become a full-time carer, then that would be natural too. Also, we grieve for what might have been, plans for retirement, for example. It is also natural to feel compassion for those who are suffering around us – other family members, such as children and grandchildren may feel the strain. We do not grieve in isolation.

It is natural to feel sad, anxious, angry, and numb during times of grief and loss. People often report feeling exhausted, low in spirits, and sometimes confused, with no idea which way to turn. Sometimes there are moments of intense emotional pain. Everyone is different, of course, and it is important to remember that grief is a normal and natural process that everybody goes through.

The "Whirlpool" model of grief



The Whirlpool model of grief was developed as an analogy of what happens during periods of trauma in our lives. The person in the canoe sails down the 'river of life' without knowing what to expect and the waterfall signifies the shock of bereavement. This can send us into a 'whirlpool' of disorganisation, breakdown, and feelings of our world 'falling apart'. At this stage, we are typically numb, and people often describe themselves as 'in a dream' or 'on autopilot'. Difficult realisations are made around this time and these are often painful. People often say that it is hard to 'make their head match their heart'. It is normal to go through all sorts of feelings whilst in this state. As we have no control over the situation, anger, denial, and anxiety are very common. People also often report feeling powerless and also guilty about not being able to do anything to aid the situation. Eventually, though, once the 'whirlpool' of emotions and the events surrounding a bereavement or situation (e.g. diagnosis) have settled down, most people are able to take stock. As time passes, your options change, the pain becomes less raw, you are able to accept the change and slowly but surely, you can move on.

It can be important to realise that such a big change in your life will change *you* in some way, and that you will never be exactly the same person you were before. A desire to be 'me again' can sometimes be unrealistic and can do more harm than good. Often the most positive reactions to grief occur when people realise that the event/situation has changed them as a person in some way.

What happens when the grief goes on too long?

As you now know, grief is a normal and natural process, and everyone is different in the way they handle change and loss. However there are times when people are unable to cope with grief on their own, and this is known as 'complex grief'.

Complex grief occurs when the period of grieving goes on for too long. But how long is too long? It isn't necessarily something you can put a figure on, but a good way to look at it is to think about *how* it is affecting your life on a day to day basis. Is it intruding on your day to day activities? Do you feel upset all of the time? Are the feelings unmanageable and intense all of the time? How do you interact with others? Complex grief tends to occur when the process gets 'stuck' on unresolved issues. It can also occur when what you do about the feelings causes more problems than it solves, for example, by trying to cope by hiding away, or by using substances such as alcohol or drugs.

Risk factors for complex grief

Risk factors for complex grief include:

- Long periods of stress or trauma in the lead up to a death: this could be described as the definition of 'caring', obviously a very stressful time with many changes involved.
- Ambivalent relationship with the deceased: this can lead to mixed feelings and difficulty understanding your emotions. This would not be uncommon in a caring situation, particularly when caring for someone whose personality and behaviour may have changed beyond recognition.

- Multiple losses: As caring for someone with dementia ultimately involves witnessing a number of changes over a long period of time, these changes could be described as multiple losses.
- Personal coping style
 - Personality/approach to life – some people are able to maintain a positive outlook no matter what life throws at them, whereas others tend to internalise their problems and blame themselves. This is not necessarily a personal failing – you just need to recognise where the problem lies before trying to tackle it.
 - Styles of grieving – we all have different styles of grieving – recognising which one is right for you and not being forced into another can help you to avoid complex grief. For example, you might be a ‘talker’ and it might help you to discuss your problems, but if you prefer not to talk, being forced to talk about your grief with someone else might just make you feel worse. Try and work out what feels right for you.
 - ‘Satori’ – this is the process of linking objects for comfort, for example, think of a child’s ‘security blanket’. When you are sad about something, or grieve for change or loss, it is quite common to find comfort in an object connected to that person, whether it be an item of clothing, a photograph, even a piece of music. This is quite normal during the grief process.
- Another risk factor for complex grief is circumstances that might delay grief. It is quite common to ‘be the strong one for everyone else’. It is important to remember that you need to grieve too. Leaving it longer will not make it any easier, and in fact might make it worse.

Bad habits

So, what kind of things should you avoid in order to prevent complex grief?

- Using food, substances (e.g. alcohol), or behaviours (e.g. excess spending) to cope with difficult feelings or situations
- Rumination/worry – we often believe that worrying is functional, and that worrying about something will prevent it from happening. We also anticipate things far too early, trying to prevent ‘step 6’ before ‘step 2’ has even happened.
- We often make the mistake of accepting what can be changed and not accepting what can't be changed. This generally leads to anger and frustration.
- Another bad habit is to have too high standards and to judge yourself too harshly. This is very common amongst carers, who carry out a very emotionally and physically demanding job under extreme pressure, often without feedback or commendation.
- Losing routine and structure – this is easily done, particularly in the early stages of caring for someone, when you have no idea what resources there are, or how to cope personally.
- Losing sleep, not eating, lack of self care – it is easy to neglect yourself, particularly when you are working hard to look after someone else. Make sure you take the time to care for yourself. If you feel you do not have this time, it is likely that you need some professional input.
- It is common for carers to try and do everything for themselves, rather than asking anyone else to help. Try not to be too independent – we all need help from others sometimes.

Wise moves for carers

- Know your rights as a carer and get support in maintaining them
- It is important to hold onto a part of your life which remains yours independent of your role as a carer. It is unlikely that you will be a carer forever, and when that role ends, you will need something that defines you as 'you'. It is therefore important to keep at least some of your independence and sense of self. In doing so, you should be able to develop a circle of social support that extends beyond the carer role. This will be very important when you are no longer a carer, as you will need people around you who are there for you, not just the person who you care for.
- Balance the stress of caring with something that you enjoy (e.g. a hobby, time out, pampering). Humans are very good at coping with stress as long as there is a balance.
- Organise a healthy routine that allows you to manage your time and cultivate healthy mental habits.
- Develop a 'plan B' for beyond your present carer role e.g. alternatives for education, income, transport, pension etc.

Healthy Habits

Assertiveness

It can be extremely useful to develop your assertiveness skills. Your role as a carer is an extremely demanding one and you need to relieve yourself of as much pressure as possible. It is therefore important to realise that you can:

- Say no and set limits kindly
- Stand your ground
- Ask for what you want or need
- Say what you think or feel when you think it is necessary
- Tell people when what they do cause you a problem

Stop worrying!!

Try switching your attention from brooding or worrying to thinking about something more positive – structure your thinking, rather than ruminating on the same thoughts over and over. Remind yourself that worrying has NO positive function. Try to develop a 'here and now' focus. Try to 'live in the moment' rather than anticipate a problem in the future.

Practicalities

Use routines and try to build in some time for yourself. Try and get outside support and make sure that you use it so that you can get time to do enjoyable hobbies or simply have some 'time out'. If you think it might be helpful, try self-expression using creative arts, sport, talking to friends, cooking, or therapy. If you have become dependent on dysfunctional coping mechanisms, try to tackle them head on.

Questions

The 'whirlpool' model is obviously based on grief associated with death. How does the model fit with the ongoing grief and loss associated with caring?

Obviously this doesn't completely fit with the whirlpool model, and in some respects, caring for someone with dementia, who changes repeatedly, can be more difficult. In the case of FTD and SD, where there are changes in personality and communication, this can be particularly difficult, and can be like losing a whole series of people at once. As the grief processes compound on each other, you may find yourself in the uncertain period of the 'whirlpool' for long periods of time.

Is it normal to feel guilty?

Many people do report feelings of guilt whilst caring for a loved one with dementia. It is natural and normal to feel this way, but it is important to remember that you shouldn't feel guilty about grieving as it is a natural thing to do.

How would a professional (clinical psychologist) help a carer in a complex grief situation?

This would of course depend on the situation and the person involved. First of all it would be important to discuss the situation and find out what problems were occurring. Also it would be important to work out the best way to help – what the individual's coping style / personality style is and what habits they needed to break. Encouraging people to listen to themselves is always helpful, as is making them understand that what they are going through is extremely difficult.

Is it normal to want the end to arrive and to feel guilty about this?

A number of our carers expressed feelings of 'imprisonment' and made reference to the fact that, unlike widowers, they cannot move on. They no longer have the partner they once had, yet they are no longer in a meaningful marital relationship. This is, of course, extremely difficult to deal with emotionally, and can easily lead to thoughts of 'wanting the end to come sooner'. This is a natural reaction to a very demanding situation. The guilt can be very intense and you should not judge yourself.

A positive note...

One of our carers offered this positive recommendation:

"My husband suffers from semantic dementia and finds it very difficult to understand what I say to him. Over the years I have increasingly found myself talking to him as if he were a child. Recently, I found that I was feeling low in spirits, and decided to do something about it. So I started to make myself think about him like he was when I first married him, before he was ill. It makes me feel better to talk to him like that rather than patronise him, like I'd started to. It reminds me that he's still the same person he was before."