NHS Foundation Trust

Patient information

Change and loss during cancer and its treatment

A cancer diagnosis or the news of recurrence or progression, and its subsequent treatment plan or prognosis, always brings change. These changes will vary for every person, but may include:

- Physical changes e.g. loss of hair during chemotherapy, changes to your body after surgery, loss of strength during treatment or if your cancer progresses
- Emotions and thoughts e.g. uncertainty or fear about what the future holds, a new feeling of being out of control or feeling alone
- Lifestyle changes e.g. change in your routine or diet, disruption to your family life or social life or your relationships, stopping or pausing work or study, financial strain due to time off work or medical costs, changes in your plans for the future
- Existential aspects e.g. challenges to your beliefs about life and death

All changes that happen to you and in your life are important. People differ in how they feel about change and how they manage it. Some are not too affected, and they manage the losses quickly. Others are more upset by the changes and losses and may experience grief: constant, difficult feelings that relate to the loss, over an extended period. There's no right or wrong way to respond to a cancer diagnosis, recurrence, progression, prognosis or to treatment effects or changes.

If you do grieve at times during your cancer journey, your feelings might include:

- Shock e.g. feeling stunned or speechless or being lost for words to talk about what you're experiencing
- Disbelief e.g. feeling that this cannot be happening to you; feeling like you're watching someone else have your treatment or even live your life; thinking that the diagnosis or news of recurrence was incorrect
- Anger e.g. towards your body, towards yourself, towards others
- Bargaining e.g. wishing that, if you are 'good' every day, then your cancer diagnosis or prognosis might be a mistake
- Guilt e.g. blaming yourself for your cancer
- Sadness e.g. feeling tearful and low

Your emotions could change from day to day, from minute to minute. You might find yourself reexperiencing feelings like anger and sadness again and again or find that you have a good day followed by a bad one. Grief can come in waves or be re-triggered by an event or situation. This is normal and does not mean you are going backwards.



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If you find yourself struggling with the psychological impact of the changes that cancer brings, you may find the following ideas helpful:

Speak to yourself with compassion

You may feel impatient with yourself or find you are comparing yourself unfavourably to other people, who on the surface seem to be coping 'better' than you. Try to remember that we're all different and cope differently. This does not mean that anyone is coping in a better way than the next person. If you find yourself getting annoyed with yourself, try to think what kind things you would say to a close friend or a child who was going through what you are going through. Perhaps you can apply the same compassion to yourself? Give it a try.

You are still you

You might feel that you have lost your 'old self' and will never feel 'normal' again. However, even though, for example, your body may have changed, or you have had to stop doing some of the things that provide meaning for you, you are still fundamentally you. The 'you' before cancer is still there even if it does not feel so; there are just other aspects of yourself that have become more dominant for the moment, such as the worried parts, angry parts or sad parts.

Good still exists

No matter where you are in your cancer and treatment pathway, there are still things that are 'good' in your life. It can be hard to remember this at times. This goodness might be being loved by family or friends, or the companionship of a cherished pet; it might be the hope that, once treatment is over, you will return to doing the things you love to do; or as life slows down as treatment continues or ends, it might be gratitude for nature, joy in the small things and feelings of peace. Whatever you value and appreciate in your life, try to hold onto the good in this and place it alongside the challenges of cancer.

Keep in touch with friends and family

It is important that you have enough time alone if you need it, to give yourself space to think and feel. However, it is also important that you keep in touch with people who know you and care about you - they can help you remember that you are still you. You might also want to make new connections where you can, perhaps through support groups.

Try to keep doing activities you enjoy

There may be times during your cancer care when it isn't possible for you to do the things you enjoy, maybe due to hospital appointments or feeling unwell. On the other hand, the weight of your grief might lead you to avoid doing activities you normally get pleasure from. Although it might feel difficult, it is important that you try to maintain some of your usual routine and activities, so you have opportunities for achievement, connection and enjoyment. If physical activities feel too much, you might try something gentler that you enjoy (see our Coping with Low Mood Information Sheet for more information and help).

Grieving is hard work and needs space to breath

Grieving can be exhausting. You might find yourself feeling very tired or struggling to concentrate. You may lose your appetite or over-eat at times. Grief is hard work and sometimes lonely. Try and give yourself the space to feel your feelings. There is no right or wrong way to grieve.





There is no timetable for grief

Grief works itself through at its own pace. It can't be rushed. For some, grief is immediate, whereas for others it is delayed. Some people start to feel better after a few weeks or months and for others the process is much longer. With time, most people find that the easier feelings like joy and gratitude start to outweigh the difficult ones, and they can more readily accept the changes in their life.

For others, time may feel too short. For instance, your cancer might have recurred or progressed or been diagnosed at a late stage and you may have been told that your time is limited. Fully grieving your losses may feel impossible in the time you have remaining, but there is always room for compassion towards yourself and, alongside it, the acceptance that things may remain unfinished. This may be enough for this moment.

Below are some links to websites with more information about loss and change after a cancer diagnosis or after learning of a change in your cancer or its treatment:

Macmillan Cancer Support: Cancer and Your Emotions

Cancer and your emotions | Macmillan Cancer Support

Cancer Research UK

How cancer can make you feel | Coping with cancer | Cancer Research UK

If you feel that you would like some professional psychological help, to assist you while you negotiate the process of change and loss, the Adult Psychological Support Service at The Royal Marsden offers time limited, cancer specific psychological support. You can either self-refer or ask somebody in your Royal Marsden healthcare team to refer you.

For more information, visit this website: <u>Adult Psychological Support Service | The Royal Marsden</u>

