

Thoughts about the organ donor

Information for patients

Some people think about the organ donor often in the early stages after transplant whereas others don't think about the donor very much at all. People have different responses and there is no right or wrong way. If you have been given this leaflet, it is likely that you have been thinking about the donor.

Emotional recovery after transplant

The first year after transplant is often a time of physical and emotional recovery. Some people are surprised to find that they feel emotional at this time. Before transplant people are often focussed on coping with physical difficulties, hospital appointments and the uncertainty of being on the transplant waiting list. After transplant, people often become more aware of their emotions as they start to look to the future and begin to move on. This can involve lots of different thoughts and feelings such as sadness, grief, gratitude, relief, increased responsibility and sometimes guilt. Steroid medication can also affect your emotions, and it is not unusual to feel tearful or anxious.

Grief, sadness and gratitude

You may have thoughts and feelings about the donor such as gratitude, sadness or grief for their family and friends. You might feel these more strongly because they may be similar to feelings you have had about your own situation. If you experience grief, sadness or gratitude the first step is to recognise these thoughts and feelings. It can help to give yourself some time to experience the feeling without pushing it away or thinking about it too much. Thoughts and feelings often pass

naturally if we do not push them away or become preoccupied with them, and people often find that they lessen over time. That said, if grief or sadness is interfering with your daily life, then please see the section overleaf for sources of support.

Responsibility and guilt

Some people also feel a responsibility towards the donor or donor's family. If you experience this it is important to make sure that you are not being too hard on yourself. Putting too much pressure on yourself to achieve certain things can lead to stress and low mood. Instead, try to be patient and kind to yourself rather than pushing yourself too much.

Sometimes people wonder why they survived while others, including the donor, died. Some people also feel guilty, which is quite common for people who have been in life-threatening situations. It is important to remember that you were not in control of the circumstances that led to you being allocated an organ or organs. It is also helpful to remind yourself of the things in life that you value. However, guilt can also be part of depression or other mental health difficulties, so if you are troubled by this you may benefit from further support (see overleaf).

Contacting the donor's family

There is the option to write to your donor anonymously. If you would like to do this, the transplant team can give you more information. Some people decide they would like to do this but find it difficult to write the letter. If you are in this situation then it is important to wait until you feel ready rather than putting any pressure on yourself. In addition, if you feel it would be helpful to have some basic information about the donor such as age and sex, you can discuss this with the transplant team.

Sources of support

If grief, sadness, anxiety or guilt are interfering with your daily activities, then you may want to speak to the transplant team about sources of support. They can also provide you with a leaflet we have prepared called 'Emotional Wellbeing: Sources of Support' that gives further information about the types of support available. Another option is to visit your GP to discuss local options for support.

Urgent sources of support

If you are experiencing a mental health crisis, then you can make an urgent GP appointment to gain support.

You can also ring NHS 111 by dialling 111 or go to your local A&E.

In addition, you can ring Samaritans any time on 116 123 – they offer a listening service.