

## Financial worries

We have Social Workers and Welfare Benefits Advisors.

To access any of this support please speak to a professional or call St Joseph's First Contact Service: 0300 303 0400.

Recommended self-help books are available in the hospice café/shop

Thai chi, meditation and relaxation and Yoga Classes are offered at the Hospice. Many are free, but there may be a low cost for others. You can find out about these by speaking to staff and keeping an eye on the leaflets in the main Community Hub or on the wards.

**Please see enclosure "external links" for more support with help and advice.**



St Joseph's  
Hospice

# Being a carer

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St Joseph's  
Hospice

The person who is ill may be very important and you want to do all you can to support them. This can become a very special time when you can become close and can make a real difference.

However, you may not be as close; it may have been a complicated or distant relationship. You may feel obliged to help, or others may have expectations about what you should be doing.

Whatever your circumstances, it is likely that you will face many challenges.

### **The early stages**

A serious illness can be stressful for all involved. It may be difficult to cope with the news of the diagnosis and treatment. In the beginning, you may all feel in a state of disbelief, and be fearful about how you will cope. Life changes for all of us when someone we are close to is ill. There is so much happening at once.

The unwell person may struggle to do the things that they always did. This may cause a lot of frustration and distress, particularly when they enjoyed their independence. There may well be money worries about being able to sustain the standard of living or housing.

### **Help and support**

Social services and health authorities can support you by providing carers, sitters and respite care. Carers can help with personal care, including washing/dressing/toileting and simple meals with visits up to 4 times a day (this support may be subject to a means tested assessment). If health is less stable and needs nursing care, more help may be available.

Sitters and respite care can provide you with important time for yourself.

St Joseph's have palliative care nurses who work alongside GPs to manage symptoms and keep patients comfortable. Marie Curie helpers can occasionally provide support overnight, so please speak to your Specialist Nurse to discuss this.

### **Emotional support**

Our palliative care Social Workers provide some emotional support. Our Psychological Therapies Team provide individual, couple and family support to adults and children who are carers, friends and family members.

### **When children are involved**

The "Elephant Kits" have been designed to support children and their carers through this difficult time. The counselling or social work teams can talk you through this and provide extra support if needed.

## Ways to look after yourself

### Taking time for yourself:

- Take time to notice what you enjoy and what helps to distract you.
- Give yourself time to have a hot drink in the morning, read, watch the football or a TV programme you wanted to see.
- Find things that make you laugh,
- Have a warm bath, or relaxing shower
- Try some relaxation and/or Mindfulness techniques
- Listen to music/sing.
- Think about spending time with people who are important to you: friends, family or religious organisation.

### Exercise

Exercise increases well-being. Get outside and have a change of environment. Consider taking a brisk walk, swimming, Tai Chi, yoga or dancing.

### Eating well

It may sound silly but many people feel as though they are so busy, they forget to eat. Eating regular nutritious food is important.

### Getting a good night's sleep

- Avoid screens before bed.
- Try lavender oils or sleep teas.

When problems with sleep become chronic, it may be worth visiting the GP to ask for sleeping tablets for a short while; this may help to break the pattern.

## Possible physical change

The person who is unwell may experience many physical symptoms. They are likely to need support at home and with hospital visits. You may find a lot of health professionals involved in your lives.

## The emotional impact of caring

Serious illness is one of the biggest stresses. Change can happen very fast and feel overwhelming. Ordinary life may already be demanding, you possibly already have responsibilities for work, family and children, as well as other elderly or sick relatives .

It is likely that it will be hard to find time for yourself, to do the things that you enjoy or to have the time to stop and process what has been going on. It may be that if you do stop, you may worry that you will become overwhelmed. This makes it very hard to rest. This can have further consequences at night when sleep does not come easily.

Stress affects us all differently; it rarely brings out the best in us! When tension rises, our behaviour changes: we can become demanding, moody, self-centred and irritable, or we can become overwhelmed and withdrawn.

When we are not at our best, we can find ourselves getting into conflict with the people who are closest to us. It is essential that we look after ourselves to try to avoid this.

## Family relationships

### Talking to each other

We often want to protect people who are unwell from additional stresses by keeping our worries from them. Although this is well intentioned, it can lead to feelings of exclusion. More often than not we find that that we share the same worries; talking about them can be a relief and can bring us much closer together.

### Couples and sexuality

Illness will affect sexual desire and how we feel about our bodies. However, it is still possible to be physically intimate. If you are on the wards, you can ask for a private room. For more please see insert on external links.

### Spending time with someone who is unwell

It can be difficult to know how to make a difference when someone is so unwell. Here are some suggestions:

When they are on the ward you may consider personalising their space by bringing in a favourite blanket or photographs. This should help them feel more at home, but it should also help staff to build stronger relationships with you all. You may like to spend time thinking about what the person enjoys: there may be favourite foods, smells, or music. You may consider giving them a hand massage. If they can no longer read, they may enjoy audio books or video games

## Ways to look after yourself

### Self-care

It can be very hard to justify taking time for oneself. When we are relaxed, we are also more resilient, problems do not seem as big and this is good for our relationships. Taking time for oneself is very important.

We may have made promises to the person who is unwell that we will always keep them at home and manage their care. However, circumstances can change, which can lead you both to change your minds.

In some instances, it can be helpful for all concerned to consider additional help at home or a move into the hospice or a nursing/residential home. When health is unstable, it can feel much safer to have people around. This can also leave you with the space to spend quality time together.

