

Facing change

living with a serious illness



Introduction

Living and coping with a serious, life threatening illness can not only affect you if you are the patient, but also your family and close friends, who may be involved in supporting and caring for you. This booklet looks at the emotional, spiritual and practical effects for those involved and suggests some ways to help with these.

The impact of hearing the news about your diagnosis and how long you may have to live can be enormous. It can be shocking and give rise to many changes and adjustments. It can touch every aspect of your life.

We are all individuals, everyone's circumstances are different and our families have their own ways of dealing with difficult situations. Family relationships may be close, tense or distant. Some people do not have a family and their friends, neighbours or those they spend time or live with may be the people that matter in life.

Throughout your 'journey' how you are coping and feeling will both vary and change. There may be periods of managing and feeling hopeful and periods of uncertainty, fear, anger, sadness or distress. At times it can feel like you are on a roller coaster of emotions. This is natural in the circumstances you are trying to cope with and there is no right or wrong way to deal with what you are all going through.

It can also feel as if your life has suddenly become more public, with various professionals becoming involved. This may feel like your privacy, independence and sense of who you are is disappearing. Therefore, exercising some control and choosing the way you want to deal with your lifestyle, health care and support may become very important to you.

Do remember that many of the feelings, changes and reactions we mention may apply to both you as the patient and those close to you.

How do you feel?

Whether you are the patient, family member or close friend it is natural to feel a whole range of emotions when life is turned upside down by serious illness, because your sense of certainty and security is affected. The shock of hearing bad news can leave you feeling numb to begin with, or feeling out of control.

Physical changes may affect the way that you see yourself. The view you have of yourself and the sort of person that you are may be challenged when diagnosed and living with serious illness. Your whole way of thinking and being may alter in ways which you don't expect. This can be unsettling for yourself and your loved ones. On the other hand, the experience can make you really focused on what matters most in life and may act as a catalyst to change your attitude and priorities.

There may be times when you experience feelings of anxiety, panic, or even dread which can leave you feeling unsettled inside or with troublesome thoughts re-running through your head. Sometimes people feel a lot of stress in their bodies, or have physical symptoms such as nausea, which are not necessarily caused by the illness but by emotional stress. Feelings of tightness in the body, a lump in the throat, 'butterflies' in the stomach or tension in the head are all signs of feeling frightened, anxious or worried.

It's also natural to feel sad, tearful or upset at times because of everything you are trying to adjust to and cope with. Some people become low in mood or feel depressed and are unable to eat or sleep well. If this happens it can make you feel as if you have no energy or

enthusiasm for anything. You may experience feeling angry, frightened or helpless at the loss of control over your health and life. Concentration and focus may also be difficult and you may not enjoy things you have enjoyed in the past.

When you experience these kinds of responses it can make it harder to manage everyday life. However, these feelings can also cause you to 'dig deep' and find the determination to choose your own way of living and dealing with your situation. We all respond to events and changes in different ways and throughout life we build and develop ways of coping. You may find in dealing with your current circumstances that you are able to draw upon hidden strengths and find new ways of managing your life, but sometimes you may need extra help or support to cope with what you are going through.

It is important to recognise that, painful as our emotions may be, they are not problems to be solved or symptoms to be cured. They are normal human reactions to life threatening situations and may include:

- grief
- sadness
- anger
- fear
- guilt
- hopelessness
- helplessness
- shame
- isolation
- feeling overwhelmed
- feeling anxious
- feeling depressed
- confusion
- despair
- uncertainty
- relief
- worry
- shock

What about relationships?

The shock waves of being given a serious diagnosis will run through your relationships. You may find yourself and the people around you behaving differently because you are all shocked by the news and may feel angry, confused or scared. Sometimes, if partners or family members cannot share how they are feeling with each other, they may seem a bit more distant than usual. People often want to protect one another and think that not sharing thoughts and feelings is the best thing. However, this can lead to misunderstandings, tension and sometimes conflict. Not sharing or finding someone you can talk to about how you feel can be very lonely.

There may be many adjustments and changes in roles and responsibilities in the family over time. Your partner or another member of your family or friends may also become your carer. This change in relationship can cause tension and take a while to adjust to. Talking to each other about what this is like and working together to overcome these changes and to make decisions about what you want

for the future can help. Often people find it strengthens their relationships.

Sometimes couples' intimate relationships are severely affected as a result of the illness and this may be difficult to discuss. This doesn't mean your partner has stopped loving and caring about you. Finding ways to talk to one another about personal and sensitive issues like this can help prevent misunderstanding, ease any additional strain this may place on your relationship and help you to keep the kind of closeness that is important to you both.

For those with children in the family it can be difficult to explain what is happening and it is natural to feel protective towards them. However children quickly pick up when something is wrong and can become worried and confused. They need simple and honest information given in a supportive way to help them understand, cope and feel involved.



Spiritual issues

Physical pain can also be made worse by spiritual issues.

Many people do give expression to their spiritual nature through their religion, however simply to be identified as a member of a particular religious group rarely tells the whole story. People who would describe themselves as religious may find that they examine their faith more deeply. This experience can be rewarding, but also challenging.

Others would describe themselves as not religious, or secular, but they are not necessarily exempt from spiritual concerns.

We recognise that the onset of serious illness can, for both patients and family members, raise many different spiritual issues. Few people have not at some point in their lives, asked themselves questions about the universe and their

place in it. These concerns can often become more prominent during stressful situations. Sometimes we try to find meaning in our experiences of life and that search for meaning can also become more immediate when faced with our own mortality, or serious changes to our future way of life.

It is quite normal for people to think deeply about their relationships, and can often take great comfort in reviewing or enriching their relationship with others in their life at this time.

Sometimes we need to be supported when dealing with these major changes. Pilgrims Hospices have full-time Chaplains to offer support to all patients and their families under our care. In addition, all the Hospice staff are trained to recognise the need for spiritual care and to respond positively to that need as it occurs.



What can change?

Living with a serious life-threatening illness affects everyone involved.

Every family is unique and practical issues that one might have previously handled without a second thought may now instil anxiety and worry. This too is normal.

The following are areas that can often cause the greatest concern:

Family - Life cycle, relationships, grandparents, children living at home, locally or far away, close and distant relatives, varying levels of support.

Housing - Mortgage, rental, moving, suitability of property, access, mobility, adaptation, court/council rent arrears, nursing home, residential home, hospital, hospice.

Job - Current employment, retirement, employer sensitivity, Statutory Sick Pay.

Finance - Car, insurance, benefits, entitlements, transport, data protection, bills, grants available, legal issues, paperwork, advocacy, writing a will.

Roles - Breadwinners, primary carers, adjustments, loss of role, role reversal.

Childcare - Children, schooling, development and understanding, their future care and security.

Independence - Loss of, relying on agencies, accessing Social Services/ Health support, lack of energy and knowledge, new fears, fear of telling friends and family, confidence, making decisions in advance.

Education - On a course, mature student, ability to continue.

Health - Physical, body image, impact on intimate relationships, mobility, hair loss. Loss of stamina and motivation affecting hobbies, pastimes and leisure activities.

What can help?

Resources such as written information, websites and books can be useful in gaining knowledge, understanding and information. We have included a list of resources at the end of this booklet for your information.

Looking after yourself through relaxation, meditation, complementary therapies, gentle exercise, pastimes and a good diet can all help your body and mind cope with what you are experiencing. (See Pilgrims Hospice Leaflet 'Time for You')

You may find that talking to family or friends about the illness and how you are feeling can help by 'getting things off your chest'. When thoughts are running round and round in your head it can be

hard to think clearly. Sharing the burden by talking over worries and concerns can help you and those close to you make more sense of things. It can also help family and friends understand what you're going through and enable all of you to decide on ways to cope and focus on what you need to get the most out of life. Sharing in this way can help bring people closer together and feel involved.

However, we often want to protect those we care about from our most painful feelings or from things that we might be struggling with. If this is so you may want to seek professional help, either to work out how to discuss these matters with your family or friends, or to support you through.



Who can help?

Talking to someone who is not directly involved or who is outside your intimate family and friends can give you a different perspective and help explore feelings and options in a supportive way. Building a relationship of trust with a professional can help ensure you receive the help you need.

There may be practical issues about day-to-day life, or the future that it would be helpful to seek information and guidance about. This can help you to work out your priorities, and plan and organise your routine in the best possible way.

Our experience has shown that receiving emotional, spiritual and practical support can help to improve the quality of life for those who are living with a serious illness, whether you are the patient, family member or friend.

All members of the Hospice Team offer support and the Hospice Counsellors, Chaplains and Social Workers will see people individually or with their family. The Hospice also runs various support groups for patients, family members and carers. People who attend these kinds of groups say they value meeting others in similar circumstances where they can talk openly about their experiences, ways of coping and to get information about services and self help.

How to get extra support:

By contacting the Hospice:

- Counsellor
- Chaplain
- Social Worker

Or by talking to any member of the hospice team about referring you to one of these team members, or giving you information about the services and programmes available to help.

Resources

Other hospice services

The services Pilgrims Hospices provide include: In patient care; supportive day care; out patients clinics with doctors or nurses; carers days; patient and family support groups; complementary therapy; healthy living, stress reduction, arts & crafts and caring with confidence programmes; out of hours advice line; counselling, chaplaincy and social work; bereavement support.

You can discuss your need for these services with any member of the hospice team involved in your care, who can then refer you if it is felt the service would be beneficial.

Pilgrims Hospices

'Guide for Patient and Families' and Leaflet 'Time for You' & 'Facing Change'.

Hospice Contact Numbers

Ashford 01233 504100

Canterbury 01227 459700

Margate 01843 233920

www.pilgrimshospice.org

Alzheimers Society

0845 300 0336

www.alzheimers.org.uk

British Heart Foundation

Information, Advice & Support for patient & their families.

Helpline 0845 070 8070

www.bhf.org.uk

Cancer Counselling Trust

For people aged 16 and over affected by cancer.

020 7843 2292

www.cancercounselling.org.uk

Carers UK

Information & advice.

Carers line 0808 808 7777

www.carersuk.org

Crossroads – Caring for Carers

East Kent Crossroads

01227 742030

www.crossroads.org.uk

Elements Project

Specialist local counselling service funded by Pearl Newman Cancer Relief Fund and counselling for young people funded by Local Network Fund.

01843 231952

Help the Hospices

Carer Information Service

www.timetocare.org.uk

Kent and Medway Cancer Networks

Website holds information about cancer, its effects and resources.

www.kentmedwaycancerguide.nhs.uk

Macmillan Cancer Support

Information, advice and support.
Publications - free to people affected
by cancer, order on-line.
Help Line 0808 808 2020
Youth Line 0808 808 0800

South Asian CancerLine

Hindi 0808 808 0100
Punjabi 0808 808 0101
Urdu 0808 808 0102
Benefits Helpline 0808 801 0304
www.macmillan.org.uk

Marie Curie Cancer Care

Care, information & advice.
0800 716 146
www.mariecurie.org.uk

Motor Neurone Disease

Information, advice & support.
0845 762 6262
www.mndassociation.org

Multiple Sclerosis Society

Information, advice & support.
0808 800 8000
www.mssociety.org.uk

Parkinson's Disease Society

Information, advice & support.
0808 800 0303
www.parkinsons.org.uk

Penny Brohn Cancer Care

(formerly the Bristol Cancer Help Centre)
Provides complementary therapies,
healing, counselling and psychotherapy.
Helpline 0845 123 2310
www.pennybrohncancer.org

Relate

Local counselling for couples, families
and Relateen for 11-18 year olds.
01227 766094
www.relate.org.uk

Rip Rap

A support website for young people
who have a parent with cancer.
0845 2030405
www.riprap.org.uk

Teenage Cancer Trust

For teenagers and young adults with
cancer, support and online forum.
020 7612 0370
www.teenagecancertrust.org

Winston's Wish

For children facing loss
08452 03 04 05
www.winstonswish.org.uk

Working Families

Information and advice about
employment/carers rights.
0800 013 0313
www.workingfamilies.org.uk



56 London Road, Canterbury
Kent CT2 8JA

t 01227 812612

f 01227 812606

Hythe Road, Willesborough
Ashford, Kent TN24 0NE

t 01233 504100

f 01233 504132

Ramsgate Road, Margate
Kent CT9 4AD

t 01843 233920

f 01843 233931

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