

Infopack for carers of myeloma patients.

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Section

Disclaimer

The information in this Infopack is provided for the benefit and personal use of anyone who provides emotional, psychological and/or physical support and care to a myeloma patient.

It is provided as general guidance for information purposes only and should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

Whilst we try to ensure that this information is accurate, we do not accept any liability arising from its use.

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Information

Who should read this Infopack?

This Infopack is for anyone providing care and support to a myeloma patient – for the purposes of this Infopack we will use the term carer. We know that research has shown that many carers don't like the term 'carer' and don't identify themselves as carers – this will be explored more on page 9. The Infopack also provides you with information and practical tips to help look after yourself and how to access the help and support you might need.

What does this Infopack contain?

This Infopack covers the key questions and topics carers of myeloma patients have told us are important to them and want to know more about.

It includes information about:

- What is a carer?
- How to look after yourself when you're caring for someone with myeloma
- Your moods and emotions
- How caring may affect your relationships with others
- Preparing for hospital visits and understanding medical information
- Work, finances and benefits
- Planning for the future

When and how should I use this Infopack?

This Infopack can be read at any time. It provides information for people who are new to caring for a myeloma patient as well as those who may have been doing so for some time. Not all of the sections may be applicable to you – you can read what feels relevant to you depending on your own needs, which may change over time.

You do not have to read the entire Infopack in one sitting; you may wish to read it in stages or use it to find answers to specific questions. Read as much as you wish, and return to the Infopack whenever you need to.

The Infopack is split into numbered sections to make specific information easy to find. We have also highlighted some key terms in orange throughout the Infopack and you can find the definitions in the medical terms explained in section 10.

Should family members and friends read this Infopack too?

We recommend sharing this Infopack with your family members and friends, especially if they are also involved in the care of the patient.

Whether you are the main carer for a myeloma patient, you help someone else who is a carer or you are reading this because you know someone who is

a carer and want to understand what they are going through, we hope you will find this Infopack helpful.

Further information and support

The Myeloma Infoline provides information and emotional support to people affected by myeloma.

You can call the Infoline on **0800 980 3332**.

Am I a carer?

Am I a carer?

This section explains what it means to be a carer and why recognising yourself as a carer can help you to receive the care and support you might need.

Many of us do not think of ourselves as carers. The National Health Service (NHS) defines a carer as someone who provides unpaid care and support to a relative or friend who is unable to manage without it.

It is estimated that 60% of people in the UK will become carers at some point in their lives so it is important to remember you're not alone.

You may not like or use the term 'carer' and instead see yourself as a family member or friend doing their bit to help a loved one. Many people think that looking after a loved one is just an extension of their role and they want to do their bit to help. However, if you are providing care and support that is emotional, psychological and/or physical that someone relies on, then you are a carer. Identifying this may help you in getting the help and support you might need now or in the future.

Caring for someone can be unpredictable, demanding and difficult to manage alongside other responsibilities, for example working or looking after a family.

People can become carers unexpectedly and may find that they have to take on tasks and responsibilities that are new to them, which can be both challenging and rewarding.

It is important to remember that caring for someone comes in many different forms. Even if you are not the primary carer (main source of care for a myeloma patient), you may still help in some way to care for a myeloma patient. The activities below are some of the ways carers can be involved in helping myeloma patients:

- Helping with housework and tasks
- Providing emotional support and companionship
- Socialising with the patient or supporting them to socialise
- Helping with transport and running errands
- Helping with medication and hospital appointments
- Finding information about myeloma and its treatments

Understanding myeloma

Understanding myeloma

This section explains what myeloma is as well as its most common symptoms and complications.

Myeloma, also known as multiple myeloma, is a type of cancer arising from **plasma cells** that are normally found in the bone marrow. Plasma cells are a type of white blood cell which forms part of the **immune system**.

Myeloma affects multiple places in the body (hence the term 'multiple myeloma') where bone marrow is normally active i.e. within the bones of the spine, pelvis, rib cage and the areas around the shoulders and hips. The areas not usually affected are the extremities - the hands and feet - as these bones do not contain bone marrow.

Most of the symptoms and complications of myeloma are caused by a build-up of myeloma cells in the bone marrow and the presence of **paraprotein** in the blood or in the urine.

Common symptoms and complications include: bone pain and bone fractures, caused by the myeloma cells which directly affect the bone causing it to become thin and weakened; tiredness caused by anaemia; frequent or recurrent infection (such as chest infections, urinary tract infections and shingles); kidney damage and **hypercalcaemia**. The symptoms and complications of myeloma can be challenging, both physically and psychologically, and can have an impact on both the person you are caring for and on you. If the person you care for is receiving treatment,

it is a good idea to know which treatment(s) they are receiving and any associated potential side-effects.

Some complications of myeloma and side-effects of treatment can be very serious and it is important to know what to do if the person you care for has developed symptoms and complications or gets any side-effects of treatment.

As a carer you will have a good idea of what is 'normal' for the person you're caring for, which can vary depending on their stage of myeloma or type of treatment. You will often be the best judge of a developing situation and may be able to pick up on subtle changes which indicate that something is not right with the patient. Acting early by speaking to a doctor or nurse when you identify something that is not normal is important - see section 6 for more information.

You can find out more about other Myeloma UK resources including information on how to cope with a diagnosis or relapse, side-effects and complications and treatments at the end of this Infopack.

Looking after you

Looking after you

This section provides an overview of why looking after yourself is very important when caring for someone with myeloma. It also includes tips on how to take some time for yourself and how to ask for help.

One of the most important aspects of caring for someone is looking after yourself.

You cannot care for someone else if you do not look after yourself properly. This is an important point that many carers often put to one side.

Adjusting to a myeloma diagnosis as well as the impact of caring for someone with myeloma will have a significant effect on you, the relationship you have with the patient as well as your relationships with others. It is easy to neglect or downplay your own wellbeing when you are looking after someone else. You can be so busy thinking about their needs and emotions that you neglect your own. You can also feel that you should be fine as it is the person you are caring for that is having to cope with myeloma.

The rest of this section will look at the different ways in which you need to look after yourself as a carer and some ideas for how to do this.

Eating well

It is important that you eat well to stay healthy and keep your energy levels up. This can be difficult when you are busy and the focus is on someone else – especially if their appetite has been affected by their illness or treatment. You may find that the person you care for has been advised to eat little and often, but that might not suit you. If you are cooking for the patient, cook a little bit extra for you and try and eat

when they do. You might want to cook and freeze meals ready to use on days that are particularly busy and stressful.

Sleeping well

It is important that you get enough sleep and rest. This can be difficult when your life changes significantly, or you are worried about something or someone. Getting enough quality sleep may require you to make some changes. If your routine at home has changed as a result of your caring responsibilities, you might need to work out what effect this change is having on your sleep patterns and try to adjust your habits accordingly.

Everyone is different and making adjustments to your sleeping habits might require trial and error before you find new habits that suit you. For example, you might not have previously taken naps during the day but now find that planning time to fit in a nap helps. If your thoughts are keeping you awake then you might find it helpful to keep a notebook beside the bed to write them down before you go to sleep or if they wake you during the night. Some people find having a warm bath or drinking camomile tea, herbal tea or warm milk helps them to sleep.

If you are caring for your partner, sleeping in the same bed as them every night may no longer be practical. For example, steroids – which are a common myeloma

treatment – can make sleeping very difficult on the day they are taken. Planning to sleep apart on these nights may help you to get some rest.

Coping with tiredness

Tiredness can gradually creep up on you as a result of your caring duties. You may be busy with lots of new tasks, for example you may have taken on the role of listening to instructions from the doctor at appointments, being responsible for household duties and also helping to keep track of when the patient needs to take their drugs. All of these tasks can be exhausting. Try to monitor or make a note of when you are most tired and ask for help if you feel you are becoming exhausted. You might need to prioritise some household duties over others as it may not be possible to get everything done.

Sometimes others will spot the signs of exhaustion before you do, so if someone close to you voices concerns, listen to them. The temptation is to keep going for as long as you can, but that may lead to making yourself ill and unable to look after the patient.

Exercise

Try to make time to take some gentle exercise – for example taking a walk in a local park can be beneficial in a variety of ways. Exercise can help you sleep better and there is good evidence that gentle exercise can

help with fatigue. Getting out of the house can also clear your head and relieve stress and anxiety for both you and the person you care for.

Keeping healthy

It is important to look after your own health when caring for someone with myeloma. Make sure that you keep up to date with regular health and dental check-ups and have the seasonal flu vaccine every year. As a carer you are entitled to the flu vaccine free of charge.

Physical care

Some myeloma patients might need help getting in and out of bed, getting in and out of a car, bathing and other activities. If you have to lift or move the patient, it is important that you know how to move and lift them safely so you do not injure yourself or them. You can be trained on safe lifting techniques to avoid injury. There are practical aids that may be available to help you safely care for a myeloma patient. For example, ask the clinic whether you can get hand rails, non-slip mats, and additional equipment to help with personal care at home.

Asking for help

Remember that asking for help or accepting assistance is not a sign of weakness or failure, it is about taking positive action.

If you are the main carer you might find it difficult to ask those around you for help. You might not want to ask them or maybe feel that you have made it clear that you need more support but no one has come forward. Perhaps you think that if family and friends have not offered then they do not have time or capacity to help.

Often people may want to help but may not understand the extent of what you do as a carer and what they can do to help and support you. It might be easier to list all of the tasks involved in caring and think about people that could help out with some of these tasks. Delegating some of your responsibilities can reduce the demands on you.

If you are a relative or friend of the main carer, you might think that they are coping just fine – or even that they are doing a great job. You may feel that offering help would be pointless, not accepted or it may imply that you think they are not doing a good job.

All of these concerns are very normal but not asking may mean the carer is not getting the help and support that they need from the people around them. This can be isolating for both the carer and the person being cared for.

Caring does not just mean looking after the medical or physical needs of someone who is ill, it also includes everyday tasks such as cooking, shopping or cleaning.

Help with these tasks can mean sitting with the person being cared for or, if they are well enough, taking them out for a walk or a drive while the main carer takes a couple of hours for themselves.

Working and caring

It is useful to ensure that your employer is aware of your situation and that you may need time off work, sometimes at short notice.

In the UK anyone who works for 26 hours a week or more has the right to request flexible working from their employer. You can also take unpaid time off work in an emergency. See section 7 for more information.

Under the Equality Act 2010 which applies to people living in England, Scotland and Wales, or the Disability Discrimination Act in Northern Ireland, carers who are also employed are protected from direct discrimination and harassment in the workplace.

Talking to others

If you have questions, or need some help and support, talk to your family and friends. It is important to make the time to speak to others and make sure you talk about you, not just the person you care for. Talking to others can provide you with space to talk about how you're feeling. There may be times when you find it easier to talk to people outside of your family or network of friends. Joining

a Myeloma Support Group, or attending a local Cancer Centre or Maggie's Centre can provide a good opportunity to discuss your feelings with other carers who are in or have been in a similar situation.

Remember that different patients have different needs, so it may not be helpful to compare yourself with other carers. There is no such thing as a 'perfect' carer and everyone's situation is different. It is important not to judge yourself against other people.

A resource of the Myeloma Infoline is the PEER Network which is available to patients, family members and carers who want to be put in touch with another carer or patient to ask questions or listen to their experiences. The Network is primarily telephone based and PEER members will respond by talking about their experience, giving practical advice and giving reassurance by answering questions. If you would like to speak to another carer, call the Myeloma Infoline on **0800 980 3332** and one of the Myeloma Information Specialists will put you in touch.

For more information see the Myeloma Support Groups Infosheet from Myeloma UK

Taking a break

Do not feel guilty about taking time out for yourself because it is important to get regular breaks from caring, both for your own wellbeing and for that of the person you care for. Plan treats and things to look forward to. Make time to see friends and relatives and carry on with some of your usual leisure time activities. This helps to avoid the build up of stress.

A break does not need to be very long and if you can plan a regular break, like a weekly class, you will also be giving yourself something to look forward to that has nothing to do with caring or myeloma. Ask those around you if they can take over from you for a regular time each week, so that you can take a break. Even if you do not think that there is anyone that you can ask, there might be other options that you can look into.

Taking a break might not just be good for you – the person you're caring for might find it easier if they do not feel like they are leaning too heavily on any one person all the time and they might also need some time to themselves.

Replacement (respite) care

As a carer it is important that you get some time to yourself to pursue your own hobbies and interests, to have a break or to catch up with friends. In addition to family and friends helping out, you may also be able to receive help for replacement care from your local social services department which is part of your local council. Replacement care can be a couple of hours a day or a few days away from your caring duties.

Replacement care might include:

- Short-term residential care for the person you care for
- Getting more paid help at home with paid workers carrying out household duties or care of the myeloma patient
- Getting someone to look after the person you care for while you go out
- The person you care for taking part in activities outside the home
- Having a holiday with or without the person you care for

Replacement care normally follows from a Carer's Assessment (see next page for more information). However, the services provided may vary between local councils. It is important to be aware that you may be charged for replacement care.

Your rights as a carer

Carer's Assessment

If you provide 'regular and substantial' care for a myeloma patient and are over the age of 18, you have the right to a Carer's Assessment from your local social services department under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. To get a Carer's Assessment, contact your local council's social services department (social work department in Scotland).

As part of the assessment you will be able to discuss the help you need as a carer. This is your right by law. You do not have to be living with, or related to, the person you care for to be assessed. The person you care for can also have their needs assessed (called a community care assessment), but if they do not wish to, you are still entitled to an assessment of your needs.

Your right to an assessment, and to the services and support you may receive, is not linked to your income or savings you may have. However, after the assessment, your local council will look at your savings and property to decide which care services you may/ will be charged for. It is important to be aware that even though your needs may be recognised, it does not necessarily mean you will get the help you need.

Social services must provide you with relevant information and reach an agreement with you on the services they are going to provide. They should respect your wishes and the wishes of the person you are caring for.

If you are not happy with how the assessment was carried out or do not think you're getting the support you need, you can contact your local council to complain. If your situation changes, you can contact social services again to have your needs reassessed.

Moods and emotions

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Moods and emotions

This section discusses how to identify and manage your moods, emotions and mental wellbeing.

As a carer, your moods, emotions and mental wellbeing are as important as the person you care for.

Many carers do not want to discuss sensitive issues because they are trying to protect the person they care for and want to avoid upsetting them. However, the longer anxieties and emotions are ignored, the harder it can be to bring them out into the open. Dealing with your moods and emotions can be difficult if you are trying to maintain a positive outlook for the person you care for as well as family members. Often as a carer you feel like you have to be strong for both the person you are caring for and family and friends. Your family and friends may often be so concerned with how the patient feels that they might forget to ask you how you are.

As a carer you are likely to experience a rollercoaster of positive and negative emotions. Feelings of anger, guilt and frustration can be tiring and consuming. It is important to recognise that these are common and natural reactions to your situation and that most carers experience them from time to time. Whatever you are feeling is okay. If you have negative feelings, try not to feel guilty about it – these are very normal.

It can be helpful to think about why you are having these feelings and to work out your own coping mechanisms; each person deals with difficult emotions in a different way and you will need to find what works

best for you. Below are some of the common moods and emotions that carers of myeloma patients have told us they experience and suggestions about how to cope with them.

Depression

Feeling down and overwhelmed affects most of us at some point but caring for a myeloma patient can be especially challenging at times. If feeling down and overwhelmed starts to affect you for longer periods of time you could be depressed.

Depression is complex and can show itself in several ways. It might not necessarily be directly caused by the patient's myeloma. It could be caused by something else or other life events but be triggered by caring for a myeloma patient. The symptoms of depression include but are not limited to:

- Tiredness, lethargy or loss of energy
- Persistent sadness, helplessness or hopelessness
- Feeling constantly overwhelmed
- Difficulty concentrating and making decisions
- Problems sleeping or changes in appetite
- Feeling desperate or panic-stricken

Talking about feeling depressed can be difficult and you may worry that other people will think that you are failing, or think worse of you. This is rarely the case. It is much more likely that other people have not realised how much pressure you are under or how overwhelmed you feel. Talking to a good friend, calling the Myeloma Infoline or speaking to your GP can help. Your GP might refer you to a counsellor or suggest other support services.

Remaining positive

Reminding yourself of all of the positive things you are doing to help and support the person you care for is important, and can give you back a sense of control. Focusing on what you are still able to enjoy with the person you care for is also important - this might be small things like going out for a coffee or spending time together in other ways.

Although many carers want to focus on keeping a positive outlook, it is important to recognise that it can be difficult and exhausting to be positive and upbeat all the time. It is especially hard to do so on the days you don't feel that way. You might think that you have to remain positive so you don't worry the person you care for or others, particularly if you feel that others will take their cue from you about how to behave with the person you care for. Remember you are allowed bad days too.

If you're having a bad day or finding it difficult to be positive, say so and ask for help. Ask another family member or friend if they can step in that day so you can take a couple of hours out to yourself. It might help you come back feeling a bit more rested and recharged.

Feeling alone

Being a carer can be isolating, especially if you live with the person you care for and have had to stop work, reduce your working hours or are no longer able to continue with some social activities. It is important to keep talking to family and friends, even if it is just on the phone. This can also help to give you another focus apart from myeloma and can be a good reminder of all of the other aspects of your life that you value.

Frustration, anger and guilt

It is very common to feel frustrated, angry and guilty when you are caring for someone. Feeling this way does not make you a bad person or carer. From speaking to other carers, we know that many people feel like this and you are not alone.

Some reasons why carers might feel frustrated or angry are:

- You cannot do the things you used to be able to do, either with the myeloma patient or on your own
- Life seems to revolve around hospital appointments and myeloma treatments
- Some spontaneity has gone as you now have to plan activities to take account of myeloma
- You know the person you care for is negatively affected by their myeloma or its treatment, for example they are in pain or are agitated
- You think 'why me?' or 'why us?'
- You feel that other members of the family do not do as much as you do
- The patient is critical of you or your care and seems ungrateful
- You feel that you have been landed with an impossible task
- Your life has suddenly changed
- You have given up your career to be a carer
- You are torn between your loyalties to the patient you are caring for and your responsibilities to other members of your family

As well as sometimes feeling angry there are many situations which may make you feel guilty. You might not even be able to put your finger on why you do feel guilty. It may be because:

- You never think that you are doing enough and set unrealistic goals
- You are aware of everything that you are not doing, even though family and friends re-assure you that you are doing the best you can
- You do not match up to your own expectations
- You meet other carers who seem to be coping better than you
- You feel that sometimes you do not like the person you are caring for
- You feel like walking away from your responsibilities
- You feel that you are only caring out of a sense of duty
- You are having time to yourself and enjoying an activity without the person you care for

It is important to talk about how you are feeling and not to bottle things up. This can be with the person you care for – they may not realise how you feel and so talking to them can get how you're feeling out into the open and also help you maintain a good and honest relationship with each other. Some carers prefer to talk to someone they do not know or who are not involved in the situation, for example their GP or a counsellor.

Alternatively, you can get support from other carers, perhaps through local carers' support groups or online discussion forums; this may help you to see that you're not alone or the only one who feels the way you do. It can also give you some time to meet others, share some stories and take time for yourself.

Below are some suggestions about how to deal with difficult emotions:

- Always ask for help and support if you're having a bad day. You will probably find that people are happy to help
- Try to get plenty of rest
- Take regular time out to yourself, for example take a couple of hours to meet a friend for a coffee or go for a walk

- Try to take some gentle exercise at least three times a week, even if it's just a walk to the shop and back
- Treat yourself to a relaxing bath, a favourite magazine or some favourite food
- Limit your alcohol intake
- Try not to feel guilty if you have negative thoughts about your situation or get frustrated
- Try to take up a hobby or maintain an existing one – this can be a good opportunity to take time out to yourself and to have something to look forward to each week

The psychological and emotional impact of living with myeloma can be just as difficult as the physical symptoms and complications for both the patient and the carer. After treatment and periods of **remission**, carers say it can be very difficult to 'get on with life' and they live in suspense, wondering how long the patient's remission will last for and if every clinic appointment is 'the one' when you are told the myeloma has returned.

Coping with moods and emotions when a patient's myeloma is no longer under control can be as difficult, if not more so, to deal with than a myeloma diagnosis. News of a **relapse** or news of a patient no longer responding to treatment (being **refractory** to treatment) has been described as having your

legs knocked out from underneath you. Regardless of when this happens, it can be difficult having to come to terms with more hospital appointments, new treatment and medical information, as well as a sense of disappointment and worry that the myeloma is not under control or has come back. Patients and carers can feel like they are back to square one and are reminded of the uncertainty and worry that myeloma brings.

When myeloma relapses and/or becomes refractory, the focus is often on the patient and how they are feeling and the emotions of the carer can be overlooked. If you are finding the news difficult, speak to someone. This might be the nurse at the clinic, family and friends, your GP or other carers. Remember the nurse specialist is there to support you too and they can also signpost carers on to other support services or resources.

Relationships



Relationships

This section explores how a myeloma diagnosis can affect your relationship with the person you care for and with others.

A myeloma diagnosis affects many people, not just the patient. It can bring significant challenges and impact on the many different relationships you and the person you care for have.

Myeloma can place a strain on your relationships in a number of ways, emotionally and physically.

It is important to remember that everyone deals with uncertainty and stress differently and the behaviour of family and friends may surprise you. You may feel tension from other family members or friends – for example you may disagree with others about the best care for the patient, especially if you are one of several carers.

Other people's reactions might surprise you for the better, as living and dealing with myeloma can bring people and families closer together and provide a common focus.

Regardless of your relationship to the patient, it is important to communicate and deal with the highs and lows together and to try to accept the changes to your life. Some carers feel a sense of loss even when spending most of the time with the person they care for. This may be because of the change in roles and dynamic of your relationship. You might miss the things you used to be able to do together that are no longer possible. It can be difficult but instead of focussing on what you're missing, try to

get something positive out of the new challenges and experiences you face together.

Relationship between you and the person you care for

Caring for a myeloma patient, whether they are your partner, sibling, child, another family member or a friend, can be both challenging and rewarding. There may be times when it feels more difficult than others, but also times when you feel more positive, particularly during periods of remission.

The majority of carers are caring for their partner. Like most couples, the challenges and stresses of life itself can mean that you already have plenty to cope with in your existing work and family life and so dealing with a myeloma diagnosis on top of that can be difficult.

In addition to hospital appointments, learning about myeloma and its treatment as well as changes to daily routines can feel challenging and overwhelming. You may also find that your role in the relationship changes. For example, if your partner is the main breadwinner they may have to stop working and you may have to start work or increase your hours at work to compensate.

It might feel like you do not have time or capacity to sit down and discuss how you're feeling and the effect it is having on you, but it is important to try to make

time and resolve any issues, for both of you, instead of letting them build up.

Many carers do not want to discuss sensitive issues because they are trying to protect the person they are caring for and want to avoid upsetting them. However, the longer anxieties and emotions are ignored, the harder it can be to bring them out into the open. This can be difficult to deal with whilst striving to maintain a positive outlook for the patient and family members.

Sex and intimacy

If the person you care for is your partner, you may find that myeloma affects the intimacy between you and/or your sexual activities. Sexuality is complex and personal, it encompasses emotional, psychological, social and physical feelings as well as sexual drive. You may find it difficult to discuss your sex life or issues surrounding sexuality, especially when there are often competing priorities when caring for someone with myeloma. However, it can have a significant effect on your **quality of life**, and on the person you care for.

Myeloma itself, its treatments, and the other challenges it can bring can all affect intimacy and sexuality. For some patients, living with myeloma can cause loss of independence, fatigue, stress, anxiety, pain and fear. For both myeloma patients and carers, coping with all of this can consume a significant amount of emotional and physical energy and leave

you both with less energy and sexual drive. Many carers also feel that they might hurt the person they care for by having intercourse with them and this in turn reduces their sexual drive.

Physical complications of myeloma and side-effects of its treatment, for example weight loss, height loss and loss of hair, can affect the patient's body image, confidence and how attractive they feel, which often impacts on sexual drive and also how attracted you feel towards them. In addition, some myeloma treatments, such as **steroids**, **chemotherapy** and **high-dose therapy** and **stem cell transplantation (HDT-SCT)** can lead to issues with fertility, arousal and impotence.

If these physical and psychological complications of myeloma cause sexual dysfunction and issues with intimacy, it is important to talk to the person you care for and explain how you feel, even if you feel uncomfortable talking to each other about intimacy. It is important to be aware that even if you do not want to be intimate, the person you care for might want to be which can cause tension. It might help to talk to the specialist nurse at the hospital who will be able to give you both support and suggest ways to help, for example talking to a counsellor who specialises in sexual issues.

It is important to keep an open dialogue with the person you care for. There are a number of ways you can express intimacy without sexual intercourse, such as holding hands, touching and massages. Remaining intimate in this way can improve quality of life and wellbeing for you and your partner, provide comfort, reassurance and support, and help you to feel close.

Starting a family or having more children

For most carers and patients, starting a family or having more children is not a concern as typically myeloma is diagnosed in those 65 years old and older. However, we do know that some patients are diagnosed much younger than this.

If the person you care for is a younger patient, it is important to be aware that some myeloma treatments can affect fertility in both men and women, and the development of babies. This can bring forward conversations about starting a family, or having more children, if you had hoped to do so in the future.

Chemotherapy can damage the testes or ovaries, which can affect the chances of conceiving a child and in female patients it can also cause premature menopause. There is a risk that the eggs or sperm produced may be abnormal up to a year following treatment. If your partner has received either of these treatments, you should not try to conceive and you

must use contraceptives until at least a year after the final treatment.

If you are thinking of starting a family or having more children in the immediate future then it is important to speak to your doctor and nurse.

If you (or your partner) are pregnant before starting treatment, or become pregnant during treatment, you must tell your doctor immediately.

It is important that you and your partner discuss your options with your doctor and nurse. Some couples choose to freeze their eggs and sperm before treatment, however this is not routinely funded by the NHS. There are other ways you can become parents and many patients and their partners consider adoption and fostering.

Your relationships with other family members and friends

Every family is different and how families deal with myeloma and caring for someone will differ.

If there are already stresses and strains within your family, these can get worse if a family member has myeloma. It is important to keep talking to each other and sharing what you are going through, especially if other family members are helping to care for the patient. Caring for someone with myeloma can bring some families closer together,

through a common focus on helping the person with myeloma.

You might find that some close friends or other family members distance themselves from you and the person you care for, which can be upsetting, but this is normally because they do not know what to say or how to talk to you. They may be waiting for you to begin the conversation about the person you care for as they may think that it isn't something you want to talk about. Giving people a quick update on how the person you are caring for is doing may be enough to help them then concentrate on you and your needs.

If you have supportive friends or neighbours and you think they might be able to help in small ways, for example by doing some shopping, dropping off prescriptions, taking your bins out or gardening, then do not be afraid to ask them for help. Suggesting a task to people can make it easier for them to know what to do.

Keep in mind that some patients may only want one person looking after them and won't allow others to help, which can put extra pressure on you if you are the main caregiver. In this situation, particularly if you are juggling other commitments and responsibilities, it might be necessary to have a conversation with the whole family, including the patient.

Talking to children or grandchildren about myeloma

Importance of talking to children about myeloma

If you have children yourself, or in your family, talking to them about myeloma – explaining what it is and providing them with the opportunity to ask questions and express their worries – can help to support them and may also help you cope better. This is true whatever the age of the children, whether you have younger children or children who have grown up, and may have their own children.

Who should tell children

If you are the parent or guardian it is usually best for you to tell your children as you know them better than anyone else. Having your partner, family member or friend with you may help you answer any difficult questions. You could also ask the nurse at the hospital to help, especially if your children are older and have more questions.

When and how to tell them

If the person you care for has just been diagnosed, you may want to wait a while to allow yourself time to come to terms with the diagnosis and to prepare answers to the questions your children may have.

Set aside plenty of time. If you have more than one child, you may decide to talk to them together so they can support each other, or individually, if there is a big difference in age.

It may be useful to use information leaflets or books to help you talk to your children. If they do have questions, try to answer them as honestly as you can and spend time to make sure they feel supported and safe; keep the language simple.

How they might react

How children react will mostly depend on how you react. You will have your own worries and fears and it is important to try to deal with these before talking to your children.

Prepare yourself for your children asking direct questions such as ‘are they going to die?’ Before talking to them, think how you will respond to this question. You might want to stress that even though there is currently no cure for myeloma, there are many effective treatments.

It is important to try to remain positive even when the future is uncertain.

Talking to your children

Myeloma UK has developed a book to help explain what myeloma is to younger children. **'Kelsey and the Yellow Kite'** tells the story of a little girl called Kelsey whose dad is diagnosed with myeloma. For more information about this book or to order a copy contact Myeloma UK.

Understanding myeloma treatment and care

Understanding myeloma treatment and care

This section discusses the treatment and care of myeloma patients, how you can help the person you care for to prepare for treatment, and an overview of who is involved in their treatment and care.

Caring for someone with myeloma will mean that you will meet a wide range of healthcare professionals who will all play a role in treating and looking after the person you care for. You may hear this team of healthcare professionals being referred to as the **Multidisciplinary Team**, or the **MDT** for short.

Knowing who's who in the MDT

The diagnosis, treatment and care of myeloma patients can be very complicated, involving different specialists and members of the MDT.

The core MDT normally includes:

- At least two **haematologists** – doctors who specialise in blood disorders and conditions. They will have expertise in treating and managing myeloma. The patient's treatment will usually be under the care of one haematologist but they may also have consultations with other haematologists in the clinic
- A **radiologist** – a doctor who specialises in the use of imaging techniques (such as X-rays and MRI scans) to both diagnose and direct the treatment of myeloma
- A **haematology** or **myeloma clinical nurse specialist** (CNS) – a senior nurse who has special training in myeloma and/or haematology

- A **palliative care specialist** – a doctor who specialises in alleviating the symptoms and complications of myeloma and the side-effects of its treatment
- A **pharmacist** - a healthcare professional who is professionally qualified to prepare and dispense medical drugs

In addition, the following specialists may be involved:

- Dietician
- Nephrologist/renal (kidney) specialist
- Orthopaedic (bone) surgeon
- Physiotherapist
- Occupational therapist
- Counsellor or clinical psychologist

The patient's GP will also remain involved in their care and the district nurse might also be involved if they require some care to be delivered at home or in the community.

Care plan and key worker

A member of the MDT, normally the clinical nurse specialist (CNS), will be the patient's **key worker** who is responsible for co-ordinating their care. The role of the patient's key worker can vary but they are typically responsible for scheduling and monitoring appointments, and providing out-of-hours contact

details. Patients should be provided with three contact numbers:

- The key worker's number and the hours that they work
- An out-of-hours number and when to use this
- An emergency number (normally when patients are on treatment and have an urgent query)

Within a month of diagnosis patients should have a holistic needs assessment with a member of the MDT (usually the CNS) which will form the basis of the patient's care plan. This care plan is used by the whole MDT and summarises:

- The treatment options discussed with the patient
- Out-of-hours contact details
- Any personal, social or religious considerations for the patient

Please be aware that if you have urgent concerns about the patient's health and cannot speak directly to the CNS/key worker it is better to call the out-of-hours or emergency numbers you have been given – if you leave a message for the CNS it may be some time before they are able to pick this up and call you back. For less urgent concerns you or the patient can also call NHS 111 for a health assessment over the phone.

Not everyone knows who their key worker is or has out-of-hours contact details for their hospital/clinic. If you are unsure about any of this information, speak to the patient's doctor or nurse next time you visit the hospital to find it out.

It is also a good idea to be prepared for unexpected hospital stays by keeping a list of what to take or having an overnight bag ready for both you and the patient. Having this ready means that if the patient has to urgently attend hospital and has to stay overnight, you have everything they will need.

Treatment of myeloma

Treatments for myeloma can be very effective at controlling the disease, reducing symptoms and improving quality of life but, as yet, they do not cure myeloma.

In general, treatment is given to:

- Reduce the levels of myeloma as far as possible
- Control the myeloma for as long as possible
- Regain control if the myeloma has come back (relapse)
- Relieve symptoms and reduce the complications the myeloma is causing
- Improve quality of life
- Prolong life

In the past the number of treatment options for myeloma was limited but, with the development of newer treatments in the last couple of decades, there are now more options available to patients.

It is important to know that not everyone diagnosed with myeloma will need to start treatment immediately and it is usual to wait until the myeloma is actively causing symptoms and complications before starting treatment.

Treatment for myeloma is often most effective when two or more drugs are given in combination. Often the drugs work in slightly different ways to control the myeloma but by being used together one drug can increase the other drug's effectiveness.

Before starting treatment

Before starting treatment, each option must be considered carefully so that the potential benefits of treatment are weighed against the possible side-effects. In most patients, overall health, age, fitness and any previous treatments will be taken into account when making decisions about treatment. The length of treatment varies depending on the type of treatment(s) being used, the stage at which the treatment is being given and the response to that treatment. Treatment is usually given over a number of weeks which may or may not be followed by a rest period - this pattern is known as a cycle of treatment.

A series of treatment cycles is referred to as a course of treatment.

Hospital appointments

As part of the treatment for myeloma, the person you care for will have regular hospital appointments and check-ups. The frequency of the appointments will depend on the stage of the myeloma and their general health and will vary for different treatments.

Most patients not on treatment will be monitored every couple of months. If they have stable disease (often called a **plateau**) or are in remission, they will only need periodic check-ups agreed with the patient's doctor, until blood tests or symptoms come back which show the myeloma is no longer under control.

If the person you care for is receiving **subcutaneous** (under the skin) or **intravenous** (into the vein) treatment, e.g. **bortezomib (Velcade®)** they will be required to go to hospital every week or a few times a week to receive treatment. If the myeloma patient is on **oral** treatment they will usually need to go to hospital at the end of the treatment cycle (this is normally 28 days).

If you drive to hospital for appointments and visits, it is worth finding out about where to park, how much it costs and if you can get help financially towards this.

Your role in myeloma treatment and care

Treatment decisions

The relationship with the patient's healthcare team will involve trust and collaboration. The healthcare team are not only there to support you as a carer, but also to involve you in the patient's treatment and care if you and the patient wish this to happen. It is important to note that for you to be involved, the healthcare team need to have permission from the myeloma patient you care for to talk to you about their treatment and care. This is required so that the patient's confidentiality is respected.

As a carer you may take on the role of researching and learning more about myeloma and the different treatments that are available. This will help you and the person you care for to communicate more easily with your healthcare team and help you both to be involved in and make informed decisions about treatment and care, should you wish to do so.

If you want to know more about any treatment the doctor has mentioned or recommended, you should take time to research or read more before you and the patient you care for make any decisions. Doctors will recommend treatment based on the myeloma activity but they may not always consider the patient's social, personal or religious circumstances or wishes.

Request a Patient diary from Myeloma UK to write down any questions and keep track of important information related to myeloma and treatment

If you cannot reach an agreement or you are unsure about the best course of treatment, you can ask for an opinion from another doctor to be sure that the treatment recommended is the best option and that all other options have been considered. You might also want another opinion if you are finding it difficult to communicate with the patient's doctor.

Doctors are normally happy to arrange for a second opinion – this can either be a different doctor in the same hospital or at another hospital. You should not feel that asking for a second opinion will offend anyone. You may, however, find it easier to approach your GP about this.

Attending appointments

It is a good idea for you and the person you care for to make a note of any questions you want to ask before your appointment and to make a note of any spells of sickness or any side-effects of treatment. It is normal to forget questions during the appointment so making a list of these in advance can help to make sure all your questions are discussed.

During the appointment, some carers like to jot down some notes which you can read over afterwards as it can be difficult to recall what was discussed with the doctor.

Some patients and carers feel that they should only ask certain questions during the clinic appointment

and feel that they would be wasting the doctor's time by talking about more holistic, social and emotional side-effects of myeloma and its treatment. It might seem that the doctor is only focused on the patient's clinical information. However, emotional side-effects of myeloma are just as important as physical ones and so it is important that you and the person you care for discuss them with the doctors.

You can also ask the doctor and/or nurse for an information leaflet to take away with you to read at home. Do not be afraid to ask for information or for clarification if there is anything you do not understand. It is important that you and the patient have the opportunity to ask questions or receive further information to be able to make informed decisions about the patient's treatment and care.

As a carer it is important to also establish a good relationship with the MDT. They are there to support you, as well as the person you care for, but they can only discuss information about the patient's treatment and care with their permission. Carers sometimes feel that they want to ask questions and find out information that they do not want the patient to hear. Some hospitals allow carers or family members to make an appointment with the patient's doctor without the patient; however, carers need the patient's permission to do this and these appointments would be outside of the clinic.

Between appointments

Keeping track of treatment

Myeloma treatment normally involves taking more than one drug at a time on different days. Drugs can have different names – a generic name and a brand name – which can be confusing (e.g. **Revlimid**[®] is also called **lenalidomide**).

The packaging and/or the colour and size of certain drugs (e.g. aspirin or paracetamol) can also look different from time to time. This can be difficult to keep track of and may put the patient at risk of taking the wrong tablets. Setting up a process at home, with support from the nurse, can help make the whole process easier. Knowing when repeat prescriptions are due can help to avoid running out over a weekend, for instance.

It might be useful to ask your pharmacy for a pill box (sometimes called a **dosette box**) or you can buy one quite cheaply from your local chemist. Your pharmacist will be able to help you to make up the box with the correct drugs on the correct days. However, chemotherapy drugs cannot be provided in a pill box so they will be given separately.

Some treatment may be given through a **HICKMAN**[®] **catheter/line**. If you want, you can be taught how to help the patient to keep this clean and reduce the risk of infection or discomfort at the entry site.

It may also be helpful to make up a chart of the patient's treatment schedules and stick it to the wall near where you store the drugs as an extra reminder. A significant issue in myeloma is adherence to treatment, particularly to oral treatment that the person you care for takes at home.

Monitoring and reporting side-effects or complications

If you have any questions or notice that the patient has new symptoms between appointments, encourage them to let their doctor or nurse know as soon as possible. If you are worried and require non-emergency but immediate advice, call the out-of-hours doctor at the hospital.

Acting early can reduce the number and severity of the complications associated with myeloma. Watch out for and contact the nurse about these, in particular:

- Signs of infection (which can vary) – temperature, shivery feeling, sore throat, painful rashes, diarrhoea, nausea, vomiting. You can buy an accurate thermometer and it is a good idea to help the myeloma patient to establish a habit of regular temperature taking and to contact the doctor or nurse if this goes over 38°C
- Symptoms that might be the result of spinal cord compression – constipation, not being able to pass

urine, incontinence, increased or sudden urge to pass urine, increased or sudden severe back pain, tingling or loss of sensation in the legs

- Any planned dental treatment for the myeloma patient. This is because some myeloma treatments can cause problems with the teeth, mouth and jaw
- New or increasing symptoms e.g. pain, fatigue

Keeping a diary to make a note of any questions you may think of between appointments can also help and this can be used to note down the patient's symptoms and patterns of symptoms and any side-effects of treatment.

Often carers mention that the steroids used in treatment combinations can cause side-effects for the myeloma patient which are difficult to cope with. These include mood swings, problems with cognition, anxiety, tearfulness, irritability and difficulty in sleeping.

It is important to remember that side-effects from steroids are temporary and can often be prevented or managed. They should resolve when the steroid treatment is stopped.

**For more information see
the [Steroids Infosheet](#) from
Myeloma UK**

'Chemo brain'

Some carers and patients also mention that chemotherapy can cause some mind and memory problems. This is often referred to as 'chemo brain'. In addition to problems with memory, it can cause:

- Mental foginess
- Problems concentrating on one thing and following a conversation
- Anxiety
- Fatigue
- Confusion

Like the side-effects of steroids, this usually subsides after treatment but some patients do complain of chemo brain long after treatment.

It also helps to keep a diary with the patient so that they can work out when they feel bad or are having problems with cognition, and also to warn family and friends that treatment is affecting their mood, so that they can make allowances.

Helping with treatment at home

Depending on the patient's treatment, you might be required to help administer some of the treatments at home, for example if they have to self-administer any injections. You will be shown how to do this by trained nurses on the day unit at the hospital, or by

a community nurse at home. You should watch the nurse first before you administer any injections, so they can show you what to do. You can also ask your nurse for information to take home.

Food and cooking

There is no evidence to support any alternative or specific diets in myeloma. Myeloma patients should therefore follow the same basic principles of healthy eating that apply to us all. Eating a healthy and balanced diet will help to maintain their muscles and strength, maintain their energy levels and may help recovery after treatment. A balanced diet is also rich in essential vitamins and minerals and can help the immune system to function more effectively.

Patients and carers should always tell the doctor about any medicines bought over the counter or supplements, such as vitamins, that the person you care for is taking. This is because some can interfere with myeloma treatment.

Several myeloma treatments and the myeloma itself can cause changes to the appetite of the person you care for and their eating patterns. Patients should try to eat little and often when they feel like food. Do not expect them to eat big portions even if they have always been a good eater. It is a good idea to freeze food in small individual portions for the person you care for to have when they feel like it.

Weight loss is also common but you can add higher calorie food to meals to help with this, for example add full-fat cream or cheese to mashed potato. If you are concerned that the person you care for is eating very little speak to their doctor or nurse who can refer them to a dietician.

Myeloma patients do not have to eat a special diet, apart from after high-dose therapy and stem cell transplantation (see next page) when they might be **neutropenic**. At this time patients have to follow a **clean diet** which means a diet with lower risk of causing infection.

If you need support about nutrition and meal preparation ask to speak to the hospital dietician.

Myeloma patients having high-dose therapy and stem cell transplantation

High-dose therapy and stem-cell transplantation (HDT-SCT) is a common treatment for younger and/or fitter myeloma patients. This can be a challenging treatment for both of you for a number of reasons.

The high-dose chemotherapy used in this treatment will cause hair loss. If this is the first time you see the person you care for without any hair it can be very upsetting. People cope differently with hair loss, some people opt to let it fall out while others decide to shave their head before treatment. Some people prefer to cover the head with a wig, hat or scarf.

HDT-SCT also involves a stay in hospital. As a carer you might feel quite helpless during this time. However, there are ways that you can help the person you care for during this time:

- Check with the hospital that will be performing HDT-SCT whether they will have ice available for the person you care for or whether you can bring and store some ice for them. Sucking ice while receiving high-dose **melphalan** can help to reduce the risk of oral **mucositis**
- Diarrhoea is a common side-effect of HDT-SCT so you might want to take along some soft quilted or shea butter toilet roll
- Do not take flowers to hospital - they can increase the risk of infection
- Most patients spend between 2 - 6 weeks in hospital after HDT-SCT. They will usually have a phone and a TV in the room/ward and will be allowed to bring in books, magazines, DVDs and CDs to keep them occupied during this time. If you are visiting, you could load some TV programmes or films on to a tablet for them to watch, or take in photos, a music player (with music and/or audio books) and magazines. It is common for patients to feel a lack of concentration during this time, so it is a good idea to bring things that are relaxing and can be picked up and put down easily
- Limit the number of visitors - the patient will be exhausted for a lot of the time after HDT-SCT. It can be helpful to agree who will visit when and have a rota - this will also give you some time off. During HDT-SCT there will be a period when the patient has a weakened immune system and visitors during this time will often be restricted to close family and friends
- As long as you check with the nurse beforehand, it may be a good idea to take food or drinks the patient might like. After HDT-SCT it is common for patients to lose their appetite or complain that they cannot taste food or it tastes different. Some patients like soup, jelly and ice cream after HDT-SCT as these are also soothing if they have oral mucositis
- Encourage the patient to drink plenty of water - this can help if they have diarrhoea and is also important for their recovery. If they do not like water see if you are allowed to bring in some squash or other drinks
- Taking get well cards or messages/notes from family and friends can help the patient to feel more positive
- Weight loss is a common side-effect of HDT-SCT, so try to prepare yourself for this. Try not to worry too much if the patient doesn't feel like eating or have much of an appetite, the

most important thing is for them to take on liquid. If you are concerned speak to the nurse and they can provide Complian® or other nutritional supplement drinks

- Take plenty of changes of underwear and pyjamas for the patient to change into
- Take open front pyjamas or tops for the patients to wear as they allow easy access to their central line without having to disturb the patients if they are asleep or resting
- Bring in snacks and boiled sweets (again check with the nurse beforehand)
- A phone/tablet charger
- It is also a good idea to take a pillow and a duvet from home, this can help the patient to feel more comfortable and relaxed

Some hospitals will have accommodation for carers while the patient is in hospital for their HDT-SCT. When you're discussing the patient's HDT-SCT with their healthcare team, remember to ask if your hospital has carer accommodation for you to stay in.

For more information see the **Infopack for living well with myeloma** from Myeloma UK

When the patient's **blood counts** are high enough, they are free from signs of infection and generally feeling better, they should be allowed to return home. Once at home, the recovery period may last for months but can vary greatly, depending on the individual. All patients who have received HDT-SCT will have a 100 day appointment to review the success of the transplant. This can be an anxious time for both you and the patient.

Following HDT-SCT, the patient will have regular hospital check-ups immediately after treatment until the doctor is happy that their blood counts continue to improve which shows their immune system is getting stronger. It may take many months after the HDT-SCT for the patient's immune system and energy levels to improve and return to normal. During this time, you may need to take precautions at home and when you are out and about, to reduce the risk of infection to the patient.

For more information see the **High-dose therapy and autologous stem cell transplantation Infoguide** from Myeloma UK

Work, finances and benefits

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Work, finances and benefits

This section explores how a myeloma diagnosis can impact on the patient's career and finances and on yours as their carer. It also explores some of the benefits and tax credits you may be entitled to.

If the person you care for is still working, it is likely they will have to stop work or reduce their hours for periods of time while on certain treatments. It might be necessary for them to change jobs if their job is very physical. Your career might also be affected - you might also have to take time off to look after the person you care for, or change the number of hours you work.

As a carer you may take responsibility for the finances of your household, or the finances of the patient if you do not live with them. This can involve a lot of paperwork, planning and budgeting which can be time consuming, especially if this is something you have not had to do before.

Work

Juggling your career and caring responsibilities can be very difficult, especially if a myeloma diagnosis leads to part-time work or brings forward retirement.

If you are a carer and are employed, you do not have to tell your employer that you are caring for someone with myeloma, however there will be times when you need to take time off, so it might be a good idea to tell them.

As discussed on page 22 the Equality Act 2010 protects carers who are employed from direct discrimination and harassment in the workplace.

Taking time off

You have the right to take unpaid leave from work to look after the person you care for, in emergencies. Emergencies include a breakdown in care arrangements or a medical emergency. This may also include carer's leave or compassionate leave.

Flexible working

You are also entitled to ask your employer if you can amend your working hours, such as changing the time of the day you work, increasing or reducing hours or working from home. Most employers are accommodating but you may have a career where flexible working is not possible.

As soon as you know more about the long-term care requirements of the person you care for, speak to your employer to find out what options are available to you. If you agree on flexible days/hours at work, this can help you plan for when you might need to arrange an alternative carer for the patient. There are other options you can also consider - for example a career break.

Even if you feel like you have had to take lots of time off, remember you're allowed to do so. If you are feeling pressure from your employer about time off, try to talk to someone in your HR department or an external organisation like Citizens Advice.

Self-employed carers

If you are self-employed, it might mean that you have more flexibility with the hours that you work and can fit these around your care responsibilities, but it can also be difficult to run a business and care for someone at the same time.

If you're self-employed it can be harder for you to receive benefits. Speak to your financial adviser or accountant if you are considering reducing your hours or stopping working.

Finances

It is a good idea to sit down with the person you care for to assess your financial situation before you make any decisions about work and retirement.

To begin with, make a list of any regular income and assets that you may have e.g. savings accounts, investments, pension schemes, endowments and existing insurance policies. Then make a list of your regular outgoings including debts and all other financial commitments that you may have.

The next step is to look for any way to increase your income or reduce your outgoings. Possible ways of doing this include: altering your mortgage payments, reducing bills by shopping around for better deals, getting advice on debt management, checking eligibility for benefits, making any relevant insurance claims (e.g. if you have income protection, critical illness or private medical insurance) and, in some cases, considering early retirement.

If the person you care for is also your partner, it may be necessary to take into account your joint income and assets as several benefits are means tested.

You may also want to update your Will or make a Will if you do not already have one, to take into account any changes in your circumstances. It is often advisable to discuss your situation with an independent financial adviser.

Mortgages

If you do not have mortgage payment protection insurance and are experiencing financial difficulties then you should inform your mortgage lender as soon as possible. Sometimes it is possible to suspend payments for a short time, pay only the interest part of the mortgage or extend the term of your mortgage. If the value of your house is much more than your outstanding mortgage then you may be able to re-mortgage your property and release some money. If you are receiving Income Support or Universal Credit then you may be entitled to help with the interest part of your mortgage repayments.

If you are applying for a mortgage with the patient you care for, it is not always necessary to give medical details. However, if life insurance or payment protection insurance are required for the mortgage then it is likely that a full medical history will have to be provided.

**For more information see the
Infopack for living well with
myeloma from Myeloma UK**

Pensions

If you have an occupational pension it may be worthwhile checking your entitlements under the scheme and whether payments will be affected if your circumstances change e.g. if you are unable to work for a while or take early retirement. If you have a private pension it may help to discuss your financial position, needs and concerns with an independent financial adviser. It might also be worth discussing if you can take early drawdown (take 25% of your pension pot as a tax-free lump sum) from your pension.

If you or the person you care for are considering early retirement on the grounds of ill health then you should discuss this with your doctor, your pension provider and/or human resources department.

Viatical settlement (also known as living benefit)

A viatical settlement is the name given to the transaction when an independent financial company buys an existing life insurance or endowment policy from a person who is not expected to live for longer than three years. This enables the person to have access to part of their policy value before they die. If the person you care for is considering a viatical settlement then it is very important to discuss this with an independent financial adviser who will be able to advise you whether or not this is the best course of action.

Debt

If financial problems mean that you are getting into increasing debt or you cannot pay off the debts you already have, it is important to seek help as soon as you can. Make sure that you are receiving all the benefits and help which you are entitled to (see following pages) by speaking to a social worker or going to your local Citizens Advice branch.

If possible try to deal with any essential debts first e.g. credit card bills with large interest rates, outstanding mortgage or rent payments and gas/electricity bills. If you are unable to pay your bills then it is important to explain to your creditors the reasons why you cannot keep up any payments – they may be prepared to accept reduced payments if they are aware of your circumstances. Further help regarding debt can be obtained from the National Debtline and from your local Citizens Advice branch.

Benefits

As a carer there are a number of different benefits and tax credits you may be able to claim – you can also help the person you care for to claim any benefits they may be entitled to.

Please note that there is an ongoing programme of planned changes to the benefits, tax credits and social care system taking place over the next couple

of years - for the most up-to-date information please download a copy of the Myeloma UK Managing your finances (benefits) Infosheet.

Before you begin to research allowances and benefits, you should use a benefits calculator. This will tell you which benefits you may be entitled to, how to claim them and how they are affected by any changes to your circumstances. You will need to have the following information to hand before you complete the calculator:

- Details of your income and your partner's income
- Any savings you have
- Any benefits or allowances you already receive
- Your council tax bill
- Details of all your outgoings

Some of the main benefits that might be available to you are listed below.

Please be aware that each allowance and benefit have eligibility criteria and some are means tested. You and/or the person you care for may not qualify for certain benefits.

For more information see the **Managing your finances (benefits) Infosheet** from Myeloma UK

Carer's Allowance

If you look after someone for 35 hours a week or more you may be entitled to Carers' Allowance which is the main benefit for carers.

Carer's Allowance is not means tested but carers have to meet certain criteria to qualify for it including:

- You look after someone who gets a qualifying disability benefit
- You look after that person for at least 35 hours a week
- You are aged 16 or over
- You are not in full-time education
- You earn less than £116 a week (after deductions)
- You satisfy UK residency conditions
- You do not receive certain other benefits

You can claim Carer's Allowance if you are 16 or over (there is no upper age limit for claiming Carer's Allowance), however this does usually stop when you reach retirement age as you will receive State Retirement Pension instead.

It is important to be aware that if you claim Carer's Allowance, this could affect how much benefit the person you care for can receive (if they are receiving means tested benefits).

In England, Wales and Scotland you can apply for Carer's Allowance online at <https://www.gov.uk/carers-allowance/how-to-claim> or by phoning the Carer's Allowance Unit on **0345 608 4321**.

In Northern Ireland you can apply for Carer's Allowance online at <https://www.nidirect.gov.uk/articles/carers-allowance-how-claim> or by phoning the Disability and Carers Service on **0800 587 0912**.

Carer's Credit

Carer's Credit protects pension rights for people who are caring for someone but not paying National Insurance contributions through paid work and are unable to claim Carer's Allowance.

To claim Carer's Credit you need to be looking after someone for a total of 20 hours or more a week. The person you are looking after should be getting one of the following:

- The middle or the higher rate of the care component of Disability Living Allowance (DLA)
- The daily living component of Personal Independence Payment (PIP) (at either rate)
- Attendance Allowance (at either rate) or Constant Attendance Allowance
- Armed Forces Independence Payment (AFIP)

If the person you are caring for doesn't get one of these benefits, you may still be able to get Carer's Credit.

Attendance Allowance

If you are aged 65 or over, the person you care for may be entitled to Attendance Allowance (also known as Personal Independence Payment, or PIP) which is a benefit to help with the costs of living with a long-term illness or disability.

If the person you care for is aged 16 - 64 they should be claiming PIP.

Some of the criteria and benefits of attendance allowance are:

- Satisfy one or more of the daytime or night-time tests (see page 88) for six months or more
- If the person you care for has a terminal illness (extra criteria apply for patients on dialysis)
- Satisfy the residence and presence tests
- Attendance Allowance may help get a council tax discount
- It is not means-tested and is paid regardless of income or savings
- It is tax free
- You can receive Attendance Allowance if you are working or studying
- There are no restrictions on how you can spend your Attendance Allowance money

- If you are also disabled or ill you can also claim Attendance Allowance even if you receive Carer's Allowance

Payment

There are two tiers to Attendance Allowance, a higher rate and lower rate.

Daytime or night-time tests

The criteria for the tests can be complicated but you have to show that the person you care for needs personal care or someone to check on them. To receive the lower rate of Attendance Allowance you need to demonstrate that the person you care for must satisfy both the daytime and night-time tests, for example by demonstrating that they need help with personal care or need to be checked at least twice a night. Alternatively patients will receive the higher rate if they are terminally ill.

Universal Credit

This is a new means-tested benefit for people of working age, who are out of work or earning a low income. Universal Credit is being rolled out across the UK and will replace several existing benefits such as:

- Income Support
- Income-based Jobseekers Allowance
- Income-related Employment and Support Allowance

- Housing Benefit
- Child Tax Credit and Working Tax Credit
- Jobseekers Allowance

Universal Credit can only be claimed in certain parts of the country and you will also have to meet the following eligibility criteria:

- Satisfy UK residency conditions
- Be 16 years and older, and younger than under State Pension Credit age
- Earn less than a certain amount
- Not be in receipt of some other benefits
- Accepted a claimant commitment

The amount of Universal Credit you will receive will depend on a number of factors including:

- Your age
- Whether you are single or in a relationship (more than one income)
- Your housing costs
- Your childcare costs

The amount varies from person to person and is based on how much you earn (which can include and/or not include other benefits) and how much you have in savings.

Until Universal Credit is fully implemented in the UK, patients will still need to claim other benefits separately.

Income Support

Income Support is a benefit available for people on a low income. Again, it is means-tested and you will have to meet certain eligibility criteria to receive it and the amount you receive will depend on several criteria including age and other circumstances. Being in receipt of other benefits may mean that you do not qualify for Income Support. In the future Income Support will be replaced by Universal Credit.

Employment and Support Allowance

The Employment and Support Allowance (ESA) is a benefit to support people who are unable to work or have a limited ability to work because of illness or disability and do not qualify for Statutory Sick Pay. There are two types of ESA: income-related Employment and Support Allowance and contributory Employment and Support Allowance. Income-related ESA is means tested while Contributory ESA is not.

You may be able to get one or both types of ESA depending on your circumstances. You do however have to have a Work Capacity Assessment as part of your application, and the amount you receive varies. Receiving ESA depends on a number of factors

including your income, the amount of any savings you might have, your age and if you're caring for someone.

Pension Credit

This benefit is available to people who are on a low income and are of State Pension qualifying age. It is a means tested benefit and there are two types of Pension Credit - Guarantee Pension Credit and Savings Pension Credit. Depending on your circumstances you might qualify for one or both parts:

- Guarantee Credit
- Savings Pension Credit

You can claim Pension Credit whether or not you are working.

Working Tax Credit

This benefit can be claimed if you are disabled and work at least 16 hours a week. Your eligibility for Working Tax Credit depends on your income and can be paid in addition to benefits for the extra costs of disability such as Personal Independence Payment. This benefit will be replaced by Universal Credit in the future.

Child Benefit

You can receive Child Benefit if you're responsible for a child under 16 (or under 20 if they are in full time education). You may have to pay a charge if you or your partner earns over £50,000 a year. Only one person can claim benefit for the same child.

Statutory Sick Pay (SSP)

If you are employed, earn at least £113 a week and are unable to work because of ill health or disability then your employer should pay you SSP. SSP is paid at a fixed rate of £89.35 a week and it is paid for a maximum of 28 weeks. If you have contractual/occupational sick pay in the terms of your employment then you may be entitled to this as well as SSP.

Blue Badge scheme

The Blue Badge scheme allows people with severe walking disabilities to park in restricted areas. The Blue Badge enables badge holders to park close to where they need to go. The scheme operates throughout the UK; however, parking concessions may be different depending on where you live in the UK. Contact your local authority to apply.

Winter Fuel Payments

If you are over the state pension age, you might also be able to get a Winter Fuel Payment to help pay your gas and electricity bills during the winter months. This payment is paid directly into your bank account.

Prescription charges

In Wales, Scotland and Northern Ireland all prescriptions are free of charge regardless of individual circumstances. In England, prescriptions are free for cancer patients on the production of an exemption certificate which can be obtained from GP surgeries or hospital clinics.

Housing Benefit

You may be eligible for Housing Benefit if you are on a low income and have to pay rent. It is a means-tested benefit and how much you receive will depend on your income and personal circumstances. You can apply for Housing Benefit if you are employed or not. Housing Benefit will fall under Universal Credit in the future.

Other benefits the person you care for might be able to claim are:

- Personal Independence Payment
- Disability Living Allowance
- Jobseekers Allowance

Planning for the future

- Incapacity Benefit
- Severe Disablement Allowance
- Benefits for the extra costs of disability

Benefit limits

In 2013 the Government introduced a limit to the amount of benefits an individual or a 'household' can receive. The cap limits change each financial year – see www.gov.uk for up to date information.

The cap currently applies to several benefits including the Carer's Allowance and many more. The Government has announced that the Carer's Allowance will be exempt from the cap although this is still to be legislated on and so at the moment, it is included in the Benefit Cap.

For more information about any of the benefits you or the person you care for might be entitled to contact Citizens Advice (contact details can be found in section 11), visit your local office or look at the benefits section of their website www.citizensadvice.org.uk/benefits.

If you need help to claim any benefit or completing the claim forms you can contact your local advice agency by contacting the Carers UK Adviceline for free on **0808 808 7777**, Monday and Tuesday, 10am – 4pm. Alternatively you can speak to the patient's key worker, social services or your local Citizens Advice branch.

Planning for the future

This section describes why it can help to plan ahead for the end of life. It also provides information about discussing the wishes of the person you care for and seeking emotional and psychological support.

Please be aware that the following pages contain sensitive information. Read this information when you are ready to do so - you can always return to this section later.

Talking together and making decisions and plans for the future can help you to take back control in a situation that can often feel overwhelming.

Making plans is an important way of ensuring that the patient's wishes about their treatment and affairs are captured while they are well enough to make decisions. Although it can be very upsetting and distressing to think about the person you care for nearing the end of life, it can be helpful to plan ahead for this. It also means that you do not have to make difficult decisions when this time comes, especially if your opinion is likely to differ from that of others involved in the patient's care.

To help you plan ahead for the future, ask the person you care for what their wishes are. There are several legal documents you and the person you care for might want to think about using to capture these wishes.

Advance Decision to Refuse Treatment

An Advance Decision to Refuse Treatment (ADRT) is a written instruction the patient can use to record specific decisions about the refusal or withdrawal of treatments, if they become unable to make or communicate decisions for themselves. It is a legally binding document when it is signed and the patient can alter it at any time, as long as they have capacity to do so.

Do Not Resuscitate (DNR) order

A DNR is different to ADRT as it specifically instructs doctors not to do cardiopulmonary resuscitation (CPR) if the patient's breathing stops or their heart stops beating. It only covers CPR and does not provide instruction for other treatments.

Power of Attorney

In England and Wales a Lasting Power of Attorney (LPA) is a legal document which allows the patient to put in writing the name of someone they trust to make decisions or manage their financial, legal or health affairs should they become unable to make decisions.

There are two types of LPA:

- For property and finance
- For health and personal welfare

It is important to note that LPA for health and personal welfare overrules an ADRT as the LPA holds the higher authority.

The LPA document varies slightly in Scotland, where it is called a Welfare Power of Attorney (WPA) and in Northern Ireland, where it is called an Enduring Power of Attorney (EPA).

Writing a Will

A Will leaves instructions about what happens to money, property and possessions (known as your estate) when you die. A simple Will is not usually expensive. It could save on legal fees that may have to be paid if there isn't one in place, and could prevent disagreements about the patient's estate amongst family members.

It is a good idea to contact a solicitor who will be able to help you draw up a Will. Some of the things you and the person you care for should discuss are who they would like to pass their estate on to and specific funeral arrangements.

November is National Will Aid month. Will Aid is a partnership between the UK legal profession and nine charities. Every November, participating solicitors waive their fee for writing a basic Will. Instead, they invite their clients to make a donation to charity. For more information go to www.willaid.org.uk

Funeral planning

It is important to learn if the person you care for has any requests about their funeral to reflect their wishes, and discuss if the person you care for does want a funeral. Some suggestions to think about are:

- Whether they want a burial or cremation
- Whether they want to have a religious service or not
- Whether they want specific songs or readings
- Whether they want flowers or a donation to charity in lieu of flowers
- What clothes they want to wear

Funerals can be expensive and some patients want to pay for their own funeral in advance by taking out a funeral pre-payment plan.

Last days

Many patients have a clear idea about where they want to be at the end of life, although this may be guided by the amount of care they need. Speak to the person you care for, as some people prefer to spend their last days at home surrounded by familiar things and in private. However, you might feel anxious about them dying at home – you may feel that you do not have the skills to look after them at home and feel they would be better cared for in a hospital or

hospice. If you feel anxious about this, you should discuss it with the patient.

In reality, the person you care for might need to be moved from home if their care needs become too complex – if this happens you should not feel like you have failed or let them down. Instead see it as you making sure they are as comfortable as possible and receiving the best possible care.

For more information on any of the legal documents mentioned in this section, or on any issues surrounding end of life please see *Planning ahead: an Infopack for myeloma patients* which can be downloaded from our website at www.myeloma.org.uk or ordered via our Infoline on **0800 980 3332**.

Bereavement

Bereavement

This section discusses adjusting to a bereavement and grieving after losing a loved one.

Please be aware that the following pages contain sensitive information. Read this information when you are ready to do so - you can always return to this section later.

Unfortunately there does come a time when myeloma progresses to a point where nothing more can or should be done to keep it under control. Ultimately, it is one or more of the complications of myeloma that is the cause of death for myeloma patients.

Following the death of the myeloma patient you have been caring for, it is important to remember there is no right or wrong way to behave - grief can present itself in many forms and everyone experiences grief differently.

Immediately after losing a loved one you may feel numb. You can find it hard to accept that they're gone and not want to do anything. It is very normal to feel a range of emotions, especially anger, which is sometimes aimed at the person for leaving you or at yourself or others, thinking you should have done more. Try not to torment yourself with feelings of anger and guilt - these feelings are a normal part of the grieving process. You will have good days and bad days when you move back and forwards between emotions and stages of grieving.

One of the most difficult times can be immediately after the funeral. There can be lots to organise and plan for a funeral which occupies your time. After the funeral is over it can feel very lonely and it may seem that everyone else is getting on with their lives without you.

Do not rush yourself or give yourself a deadline for when you have to 'get back to normal'. Take each day as it comes and do not put yourself under unnecessary pressure to do too much too soon; you need time to adjust and look after yourself.

For most people bereavement and grief is emotional and psychological but some people also develop physical symptoms such as nausea, pain, dizziness and tightening in the throat and chest. This can be quite scary and unexpected but like most emotional and physiological symptoms, they should improve over time. If they do not you should speak to your GP.

Some people also feel a physical presence of the person they have just lost or have vivid dreams about their loved ones, which can be very upsetting. These are normal reactions to grief and can occur at any time.

Delayed grief

Some people find they do not feel grief and loss immediately after the death of a loved one. It can be upsetting for some to find that they do not react and behave in the way they thought they would. This is often because they cannot move past feeling

angry. If you're feeling like this it is very important to talk to someone and allow yourself to have different emotions beyond anger.

Very rarely, a small number of people develop suicidal thoughts and feel like they cannot go on or feel like their own death will bring them closer to their loved one. If you ever have suicidal thoughts, talk to your GP or someone you feel you can trust - you might need professional counselling, or require medication for a small period of time.

Talking

It is important that you do not bottle up how you feel and that you talk to others, whether that is a friend, another family member or a trained counsellor. Do not be afraid to show your emotions. Releasing emotions and crying can even help you feel a little bit better, and get things off your chest. It is good to develop a support network, even if you do not feel like talking and just want some company - you can also seek out local support services, meetings and forums. Talk to your GP to find out more information. Your GP can also put you in touch with a bereavement counsellor if you feel you need more one-to-one time with a trained professional. There are also several organisations, such as Cruse, who run groups for people who have lost a loved one. See section 11 for more information.

Talking to children

It can be difficult enough to come to terms with the loss of a loved one, especially if you're on your own. Children will also experience a range of emotions and grief, especially older, teenage children who are already dealing with changes in their lives. There are many bereavement support services available for teenage children like **Hopeagain** and **Winston's Wish**.

Younger children will also find it difficult to come to terms with the loss of a loved one. Small children might be too young to understand or know what death is. You might have to remind them several times or leave this to a time when you think they are old enough to understand.

Living your life again

After losing a loved one many people feel like their life will never be the same again. The truth is that life will not be the same without your loved one in it, it will be different but you can still live your life. Coping with the loss of a loved one takes a long time but there will come a point when you do not feel as numb and your grief is not quite as strong. This doesn't mean you will forget the person - you won't, but it is important to find a balance where you can live your life again.

There isn't a time frame for how long grief will last, but over time the feelings of loss and grief ease. Even at this point feelings of grief can be triggered

at particular times and places, such as their birthday or a favourite restaurant. At times like this you should remember to celebrate their life or visit somewhere that was special to both of you. You might want to mark special occasions by visiting where they are buried or where their ashes were scattered.

Myeloma UK can also help you through grief and bereavement in a number of ways. You can chat to other families in the End of Life and Grief thread on our online Discussion Forum or call the Myeloma Infoline to talk to a Myeloma Information Specialist.

Medical terms explained

one

two

three

four

five

six

seven

eight

nine

ten

eleven

twelve

Medical terms explained

Blood count

The number of red blood cells, white blood cells and platelets in a sample of blood.

Bortezomib (Velcade®)

A proteasome inhibitor drug which is given either by intravenous infusion or subcutaneous injection.

Chemotherapy

A type of drug intended to kill cancer cells. Chemotherapy drugs can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

Clean diet

A diet recommended for people who have a compromised immune system. Excludes 'higher risk' foods e.g. soft cheeses, live yogurts and pâté.

Clinical Nurse Specialist (haematology or myeloma)

A healthcare professional who provides specialist and direct care to patients. CNSs may also serve as consultants and assist other healthcare professionals and work to improve patient outcomes.

Dosette box

A box used to organise drugs into compartments by day and time.

Haematologist

A doctor who specialises in the study of blood and blood-related disorders.

HICKMAN® catheter/line

The brand name for the catheter (tube) which is inserted under the skin in the chest into a large vein just above the heart. It can be kept in for several months and is used to administer treatments and to take blood samples. Also known as a central line and a central venous access device.

High-dose therapy

Treatment with high doses of chemotherapy given intravenously, usually via a central line (such as a HICKMAN® line), or a PICC line, prior to patients receiving healthy stem cells as part of the stem cell transplantation procedure. Also known as conditioning treatment.

Hypercalcaemia

A higher than normal level of calcium in the blood, which may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion.

Immune system

The complex group of cells and organs that protect the body against infection and disease.

Intravenous

Into a vein.

Key worker

A member of the multidisciplinary team (MDT), usually a clinical nurse specialist, who will be the patient's primary point of contact during treatment and care.

Melphalan

A chemotherapy drug which is given orally or intravenously.

Mucositis

Pain and inflammation of the lining of the mouth and/or gastrointestinal tract.

Multidisciplinary team (MDT)

The team of health and social care professionals who provide patient care.

Neutropenia

A reduced level of neutrophils, a type of white blood cell important for fighting bacterial infection.

Oral

By mouth.

Palliative care specialist

A doctor or nurse who specialises in treatment and care that concentrates on preventing and relieving symptoms and improving quality of life.

Paraprotein

An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease. Also known as M protein.

Pharmacist

A healthcare professional who prepares and dispenses drugs.

Plasma cells

A type of white blood cell that produce antibodies (immunoglobulins) to fight infection.

Plateau

A period of time when the myeloma, and the paraprotein level, is relatively stable.

Quality of life

A term that refers to a person's level of comfort, enjoyment, and ability to pursue daily activities. It is a measure of an overall sense of wellbeing.

Radiologist

A healthcare professional who specialises in using imaging techniques to diagnose and treat diseases.

Refractory

Disease that has failed to respond to treatment or has stopped responding to treatment.

Useful organisations

Relapse

The point where disease returns or becomes more active after a period of remission or plateau (often referred to as stable disease).

Remission

The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Revlimid® (lenalidomide)

An immunomodulatory drug which is given orally.

Steroids

A group of hormonal substances produced by the body. They are also produced synthetically and used to treat many conditions.

Stem cell transplant

The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

Subcutaneous

Under the skin.

Useful organisations

Carers UK www.carersuk.org

0808 808 7777

Provides advice, information and support for carers.

Citizens Advice www.citizensadvice.org.uk

England: 03444 111 444

Wales: 03444 77 20 20

Scotland: 0808 800 9060 **N. Ireland: call local Bureau**

Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support www.macmillan.org.uk

0808 808 0000

Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's www.maggiescentres.org

0300 123 1801

Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind www.mind.org.uk

0300 123 3393

Provides advice and support to empower anyone experiencing mental health problems.

NHS 111 Service www.nhs.uk/111

111

Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

About Myeloma UK

Myeloma UK is the only organisation in the UK dealing exclusively with myeloma.

With Myeloma UK you can...

Call our **Myeloma Infoline** for practical advice, emotional support and a listening ear:
UK: 0800 980 3332 Ireland: 1800 937 773

Learn about myeloma from experts and meet others at our **Patient and Family Myeloma Infodays**.

Order or download our information, which covers all aspects of myeloma – call **0800 980 3332** or visit **www.myeloma.org.uk**

Find your nearest **Myeloma Support Group** to meet up and talk to other people face to face.

Visit **www.myeloma.org.uk**, a one-stop-shop for info on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.

Watch **Myeloma TV** which hosts videos about myeloma presented by experts, patients and family members.

Use the **Discussion Forum** for the opportunity to share experiences and advice about living with myeloma.



We need your help

Thanks to our generous supporters we are able to provide information and services to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.

Myeloma UK receives no government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a donation**
 Online at **www.myeloma.org.uk/donate**
 Over the phone **0131 557 3332**
 Or by posting a cheque payable to **Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG**
- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness. However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 557 3332** or email **fundraising@myeloma.org.uk**
- **Leaving a legacy** – gifts from Wills are an important source of income for Myeloma UK and will help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments

“

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do. ”

Judy Dewinter – Chairman, Myeloma UK



For more information about myeloma and Myeloma UK contact:

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Edinburgh
EH7 4HG

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Charity number SC026116

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1800 937 773 (Ireland)
www.myeloma.org.uk

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All Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.

To fill in a short survey about our patient information online, please go to www.myeloma.org.uk/pifedback

If you'd like to feedback specifically about this publication, please email myelomauk@myeloma.org.uk

For a list of references used to develop our resources, visit www.myeloma.org.uk/references

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