A Myeloma UK research report on the experiences of myeloma carers in the UK
Acknowledgements

Myeloma UK extends its gratitude to everyone who contributed to this research.

Thanks in particular are due to Patient and Carer Research Panel members: Steve Hyne, Alison Love and Georgina Groves, who provided invaluable advice throughout the design of the research.

Thank you also to the Picker Institute Europe who were commissioned to co-design the research and who conducted it on our behalf.

We are also very grateful to the Myeloma Support Groups around the UK and the Basil Skyers Foundation for helping to publicise the survey.

Above all, thank you to the 374 carers who took part in the survey and the 20 carers who took part in the interviews for sharing their experiences with us. The issues concerned are not easy to talk about, and this research is much richer for their openness in doing so.
Foreword

From having met so many friends and relatives of patients over the years, it’s clear that myeloma can considerably affect their lives, both from taking on caring roles to the emotional and practical impact of dealing with life with myeloma.

This is why Myeloma UK, from its inception, has been focused on supporting and improving the lives of all those affected by myeloma, carers as well as patients. We are constantly listening to and learning from those directly affected by myeloma so that we can make their lives better.

I am very grateful to everyone for sharing their experiences so honestly in our research. I was struck by how much positivity came through from those providing care and support to a relative or friend with myeloma, but also by the heartbreak, isolation and uncertainty that many in this situation feel.

This research provides evidence and insight into key issues experienced by carers, and in particular the considerable emotional strain that many experience on top of other day-to-day practical effects on their lives. Carers share the concerns of patients, but also have their own individual concerns and needs that come from living with the implications of myeloma and taking on a caring and supporting role.

In many ways carers are an invisible workforce. They play hugely important roles in improving outcomes and quality of life for their relatives and friends with myeloma. I’ve met many patients who say they wouldn’t have managed the burden of dealing with difficult treatments and side-effects without the practical and emotional support of their relatives and friends. This makes it even more vital that carers too have the support they need to look after themselves.

We all must do our utmost to recognise the impact of caring and the needs of carers. Research like this is invaluable in helping us assess how we can best support everyone affected by myeloma, from providing information, a listening ear and access to a variety of support with carers in mind.

First and foremost the report findings confirm a critical need to think outside the box and find new ways to provide support and information to carers. We are pleased to launch our new Infopack for carers of myeloma patients, the content of which has been directly informed by this research and look forward to implementing a range of other new initiatives in the coming months.

I hope that all those involved in supporting myeloma patients and their families will benefit from the research and use it to discuss how together we can meet the challenges posed in the report.

Eric Low
Chief Executive, Myeloma UK
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Introduction

This report provides insight into the experiences of individuals who provide care and support to myeloma patients.

We conducted the research to build on our current knowledge and to better understand the experiences and perspectives of those who provide informal care and support to relatives and friends with myeloma.

This evidence is critical for the continued development and improvement of our own services to meet the needs of carers and our work to inform practice and standards of care across the UK.

Methods

The research was designed with the input of myeloma carers, Myeloma UK and the Picker Institute Europe. The Picker Institute Europe was commissioned to undertake the research on our behalf and provide an independent detailed research report. The research comprised three fieldwork stages:

1. Initial in-depth interviews with carers to determine the themes and topics for the survey.
3. A second stage of interviews with carers to explore issues from the survey in more depth.

Participants in the survey came from a wide range of circumstances:
- 71% are providing care or support to a spouse or partner, 23% to a parent, 2% to a son or daughter, 3% to another relative and 1% to a friend
- 75% are female and 25% are male
- 53% are aged over 60, 22% between 50 and 60 and 17% are aged under 50
- 39% who are caring for a spouse or partner also have children living with them
- 35% have a disability or long-standing condition of their own
- 75% are caring for a myeloma patient who is over 60, 17% between 50 and 60 and 8% under 50
- 32% have been caring for less than two years, 41% for between two and six years, 16% for between 6 and 10 years and 11% for more than 10 years
- 57% said that at the time of completing the survey the patient they care for was undergoing myeloma treatment
About this report

This summary report highlights the key findings across the following themes:

- The support provided by carers
- The impact on the lives of carers
- Carers’ access to support and barriers in the way

The full research report, including the anonymous data and quotes, is available from Myeloma UK.

While we understand that many relatives and friends who support myeloma patients do not see themselves as carers, we use the term ‘carer’ in this report due to it being a widely used and understood term.

We hope this report will be of particular interest to carers, both those who participated in the research and others who may recognise aspects of the findings from their own experiences. We hope it will show carers that they are not alone and encourage them to seek information and support from Myeloma UK and others.

We also hope the report inspires the myeloma professional community to continue to assess how best to support carers and work with Myeloma UK to meet the challenges raised in the report head-on.
What help and support do carers provide to patients?

Our research suggests that looking after a relative or friend with myeloma involves a variety of roles and that some of these can be particularly difficult. Carers spoke of having to feel emotionally strong and be positive for their relative or friend.
This is challenging, with relatives and friends dealing with their own uncertainty and stress. Although physical aspects of caring are important aspects of the caring role, providing emotional support was found to be both the most common aspect of caring and the hardest to do.

As shown in Figure 1, nearly all survey participants provide emotional support to their relative or friend. Accompanying myeloma patients to appointments (89%), running errands (81%), and sourcing information (78%) and carrying out household chores (76%) are also major elements of care and support.

10% of survey participants mentioned they provide ‘other’ kinds of support. These included gardening, helping with walking, and trying to make the lives of their relative or friend as normal as possible.

Some carers described how they would be providing some aspects of this care and support anyway, whereas other aspects are related specifically to their relative or friend’s needs since being diagnosed with myeloma.

“I try and make suggestions about things that will make my parents’ lives easier. I find this really difficult because it’s parent/child role reversal. Things like cooking, cleaning and taking my mum out are things I would do even if she was in perfect health.”

Figure 1 - Elements of care and support provided by research participants

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support - talking and listening</td>
<td>98%</td>
</tr>
<tr>
<td>Accompanying to appointments</td>
<td>89%</td>
</tr>
<tr>
<td>Running errands</td>
<td>81%</td>
</tr>
<tr>
<td>Sourcing information</td>
<td>78%</td>
</tr>
<tr>
<td>Household chores</td>
<td>76%</td>
</tr>
<tr>
<td>Providing transport</td>
<td>69%</td>
</tr>
<tr>
<td>Helping to manage side-effects and symptoms</td>
<td>67%</td>
</tr>
<tr>
<td>Talking to healthcare professionals on the patient’s behalf</td>
<td>58%</td>
</tr>
<tr>
<td>Helping to record side-effects and symptoms</td>
<td>48%</td>
</tr>
<tr>
<td>Giving medication, changing dressings and other healthcare tasks</td>
<td>48%</td>
</tr>
<tr>
<td>Managing finances</td>
<td>46%</td>
</tr>
<tr>
<td>Helping with washing, bathing and feeding</td>
<td>31%</td>
</tr>
<tr>
<td>Babysitting or caring for children or other dependants</td>
<td>12%</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
</tr>
</tbody>
</table>
74% of those who provide care and support to a relative or friend with myeloma do not see themselves as a ‘carer’.

Our research found that, despite the considerable ‘caring’ roles performed by relatives and friends, only a minority use the term ‘carer’ to describe what they do. Many of those who do not identify with the term explained that they think of a ‘carer’ as someone who only provides physical care. Others said that what they did was just a natural part of being a partner or other relative.

98% of carers provide emotional support to their relative or friend with myeloma.

Many carers explained that the emotional support they provide is often to support the patient through periods of anxiety, frustration and mood changes associated with treatment side-effects.

Unlike practical aspects of support that can change over time depending on patients’ physical circumstances, emotional support is more constant. While just over half of survey respondents said that less of their time overall is taken up by providing care when the patient is off treatment a third said the time they spend caring is unaffected by the patient being off treatment.

“Sometimes it’s tiring. Sometimes I feel sad. Sometimes I think about all the hours I have spent at the hospital and how I might have used that time otherwise. But it’s all the price of love.”

“The steroids just messed with his emotional and mental state so hugely.”

“Mostly, it is about being there with my partner. She is scared by the whole process and I offer her a source of strength, a sounding board and somebody to bounce against.”
Carers explained that emotional support is such an important part of their role due to the stress and uncertainty of not knowing when a relapse may occur and then dealing with relapses that do occur.

52% of all carers find emotional support the hardest type of support to provide.

As well as being the most common form of support carers provide, the carers in our survey indicated that emotional support is also by far the hardest to give.

Some carers said they find this difficult because they feel they always need to be emotionally strong for their relative or friend even though they too are affected by the situation.

“He was getting over it physically, but psychologically he was bursting into tears all the time and that is hard.”

“I find the psychological support more difficult than the physical side, because when somebody gets down in the dumps, it’s just a horrible time. The thoughts that go through their head and the things that they say are awful.”

“You’re trying to support them and your heart’s breaking too.”
What is the impact on carers’ own lives?

Our findings show that relatives and friends are affected in many different ways as a result of both caring and dealing with the day-to-day implications of myeloma. Many in this situation mention changes in their social life, relationships, income, and wider family dynamics.
Our research highlights a significant emotional effect on those undertaking a caring and supporting role. Carers willingly put the needs of their relative or friend before their own but many carry a heavy emotional burden. The emotional impact of caring is more constant and in most cases harder to manage than the other effects on carers’ lives.

Emotional impact on carers

The biggest impact reported by carers on their own lives is an emotional impact, with 94% of carers affected this way. They told us that the uncertainty of myeloma is a major factor and that it is difficult to adjust to ‘living from day to day’.

“I feel angry that I’m not going to get the future I wanted, but the hardest thing to feel is how my life at the moment is in limbo.”

Figure 2 – Areas of carers’ lives that are affected by caring

- **EMOTIONAL**: 94%
- **SOCIAL**: 59%
- **PRACTICAL**: 50%
- **PHYSICAL**: 47%
- **RELATIONSHIP WITH THE PERSON WITH MYELOMA**: 47%
- **WELLBEING**: 45%
- **WORKING LIFE**: 39%
- **FINANCIAL**: 31%
84% of carers always put the needs of their relative or friend with myeloma before their own.

An overwhelming majority of carers said they put the needs of their relative or friend before their own. 89% of female carers felt this way compared to 69% of male carers. Those who had been caring for less than a year were slightly more likely to agree with this (92%) than those who had been caring for more than a year (82%).

Some carers explained that putting their or other family members’ needs on hold could cause tension and stress in the family, particularly where the lives of dependent children were affected.

89% of carers feel they always have to be positive.

Many carers said they feel they always need to be positive around the patient, explaining that this is a strategy to provide emotional support to their relative or friend. However, some carers said that striving to do this has a considerable strain on them.

Others said they feel guilty when they are not able to maintain that positivity and that this feeling of guilt can cause additional stress and anxiety.

58% of carers often feel they have nobody to talk to.

Some carers told us they cope with the emotional strain of caring by talking to others, either with carers in a similar situation or friends who can provide them with support with their own worries.

However, many feel they do not have the opportunity to share their experiences, feelings or worries with others and this can lead to them feeling lonely and isolated. More female carers (61%) said they feel this than male carers (45%).

“I think because when I’m with Dad you just have to put on this persona that, ‘oh it’s fine, everything’s OK’, but when I’m away from him that’s when the worry sinks in. The perspective and attitude towards it that I have in front of him and away from him are two totally different things.”

“It’s perfectly normal to have bad days and there’d probably be something quite wrong with me if I didn’t, but that doesn’t stop me feeling guilty for it though.”

“He needs me as a rock and most of the time I’m fine, it’s just the odd time I feel a bit worn out with it all.”
Impact on family relationships

Many of those interviewed described a changed relationship with the myeloma patient. Some interviewees explained that a greater physical and emotional dependency on them had affected the dynamic of their relationship.

Two-thirds of carers who are partners to the patient also said their sex life had been affected. Interviewees mentioned that treatment side-effects and fatigue particularly affected their ability to be intimate with their partner.

Some carers said that myeloma has changed their relationship in a more positive way, as they spend more quality time together and are more aware of each other’s feelings.

“Obviously it has had massive implications for our future, but you know it’s there and we can’t change that. We can just live in this moment we’re in and make the best of it really.”

“When you’ve got that much structural damage to the body, it affects the ability to be intimate. You couldn’t even give him a cuddle or anything because every movement hurts.”

“It makes you not quite so caught up in what is - in the grand scheme of things - quite insignificant day-to-day fluff and to focus on what’s really important.”

57% of carers get upset or angry that their life will not be as they planned.

Carers who are under 50 were more likely (66%) to say they felt anger and sadness about life not being as they planned than carers aged over 50 (48%). Females were also more likely (61%) to report this than males (39%).

Overall, just over half of all carers said they feel upset or angry that life will not be as they planned. Some described a sense of anger and frustration at having to relinquish certain hopes and plans for the future. Others described a sadness caused by observing what their relative or friend has lost as a result of having myeloma.
Carers who are also parents of dependent children described the impact on their children’s lives. Some worried that their children received less time and attention while others noted a changed relationship between their children and the parent with myeloma.

Several carers said that their children experienced anxiety and that living with a parent with myeloma has had a considerable emotional impact on them.

Of those who have children, almost half of survey respondents (47%) said their children find living with someone with myeloma difficult to cope with.

Overall only 20% of carers feel their children are unable to do things other children their age do. Interviewees explained that they try to keep a sense of normality for their children but that sometimes this is impossible, for example if the patient is feeling especially unwell.

Some carers also described effects on wider family relationships.

“In the early days it was very difficult for [the children] to know how to communicate with dad when he’s feeling poorly and just to react to a different way of being as a family.”

“We don’t have a big family or friends that support, so it’s basically just the three of us and that’s an added pressure. [Mum and I] argue a lot and a lot of it is down to the fact that we’re almost fighting to care for him.”

“What I need is people around me to laugh with, about normal stuff.”

Impact on carers’ social life

60% of carers say that their social life has changed for the worse.

Many carers report a change in the way they socially interact with others. Some feel less able to go out socially particularly when the patient is unwell, or feel guilty for doing so. Partners explained that it is difficult to make new friendships because they have less opportunity to go out and meet new people.

Others indicated that relationships with friends had changed because of their caring role and because friends could not easily understand their situation.

Other carers, however, receive valuable support from their friends, either as a means to share their worries, share caring tasks or provide distraction and a sense of normality.
Impact on carers’ work and finances

25% of carers who were in work say they have been unable to work or had to retire early to care for the person with myeloma.

For most carers, the actual or potential loss of income was the main source of financial worry raised in our research. Myeloma can affect both patients’ and carers’ working lives. Younger carers in our survey were the most likely to say they had been unable to work or had to retire early due to their caring role. For some this was a double impact if the patient was also no longer in work.

Some interviewees explained that a loss of work or income can have a knock-on effect on other areas of their lives, increasing the likelihood of social isolation or experiencing stress and anxiety.

However, of those carers who are currently working, 78% said their employer had been supportive with letting them work flexible hours to manage their caring role. Carers who receive support from their employer said this helped to minimise the impact of caring on their life.

Impact on carers with a disability or long-term condition

One in three participants in our survey have a disability or long-term condition themselves. These respondents were more likely to report that caring for a relative or friend with myeloma had a physical strain on them as well as a greater impact on their wellbeing.
What support do carers access?

Our research shows how complex and difficult caring can be. Here we report on the different ways relatives and friends of myeloma patients access support for themselves and the challenges in accessing the support they need. The findings suggest that most of the support accessed by carers relates to Myeloma UK information and support services, followed by informal support from family and friends.
Healthcare professionals, support groups, online forums and social media networks also provide valuable sources of support to carers. Very few carers access any professional counselling support. Many carers would like more opportunity to talk to someone about their own worries and concerns.

Figure 3 shows that carers access a variety of different sources of support.

In interviews many carers said they find it particularly helpful to speak to other carers and compare notes and share experiences.

“There’s a social media group and I find that’s brilliant. Just being on there and seeing other people posting things, and I’m thinking ‘I’ve been through that, I’ve seen that, I know where that’s going’. And I feel I’m in a community rather than just being someone by themselves.”

Figure 3: Sources of informal support accessed by carers

<table>
<thead>
<tr>
<th>Source of Support</th>
<th>Access Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>MYELOMA UK</td>
<td>73%</td>
</tr>
<tr>
<td>FAMILY MEMBERS</td>
<td>56%</td>
</tr>
<tr>
<td>FRIENDS</td>
<td>50%</td>
</tr>
<tr>
<td>CLINICAL NURSE SPECIALIST</td>
<td>47%</td>
</tr>
<tr>
<td>MYELOMA CONSULTANT</td>
<td>46%</td>
</tr>
<tr>
<td>GP</td>
<td>41%</td>
</tr>
<tr>
<td>MYELOMA UK ONLINE FORUM</td>
<td>25%</td>
</tr>
<tr>
<td>SUPPORT GROUPS FOR PATIENTS AND CARERS</td>
<td>22%</td>
</tr>
<tr>
<td>SOCIAL MEDIA</td>
<td>19%</td>
</tr>
<tr>
<td>OTHER NHS PROFESSIONALS</td>
<td>12%</td>
</tr>
<tr>
<td>ANOTHER CHARITY</td>
<td>11%</td>
</tr>
</tbody>
</table>
While carers often find that their relationships with friends changed, one in two carers still indicate that friends are a main source of support for them. Male respondents to our survey were less likely to access friends as a source of support (32%) than female carers (56%).

Younger carers (aged under 50) were more likely to say they did not use face-to-face support groups.

43% of all carers say there are times when they need additional support to provide care.

Carers who are newer to caring were more likely to say they needed additional support than those who have been caring for longer.

Examples of additional support needed include having someone to talk to and get reassurance from and having a break from caring. Some carers also mentioned wanting more information and practical support to administer medication and help manage side-effects.

Some carers spoke about patients not wanting to accept practical support or help from others. Just under two-fifths of carers said they had asked for help but their relative or friend will not accept it.

39% of carers would like to have been offered professional support at the time the person with myeloma was diagnosed.

Not all carers said they wanted or needed any professional support (e.g. counselling), however two in five carers would like to have been offered professional support at the time of diagnosis. Those who were offered and took the professional support found this helpful.

“It’s difficult finding people to talk to that are our age, because we are quite young to be dealing with it.”

“When there has been external support he generally pushes it away and we’ve fallen by the wayside again.”

“I was trying at that point to deal with work and home and fit everything in. I found it very useful just to talk things over and get things straight in my head, about me as a person.”
42% of carers were not given enough information at diagnosis about how myeloma may affect them.

Over two-fifths of participants in our survey were not given enough information about myeloma and how it might affect them when the patient was diagnosed. A higher proportion of carers with a disability or long-term condition themselves were more likely to say they did not receive enough information.

Carers talked about feeling unprepared for what would be involved in supporting someone with myeloma and in some cases wanting more information about myeloma than the patient themselves.

Most carers mentioned Myeloma UK as a source of helpful information, including the Myeloma UK website, Infodays and Infoline.

49% of carers are not able to speak to healthcare professionals on their own about their worries but would like to.

Some carers find it difficult to speak to healthcare professionals on their own. One reason for this is where the carer is unable to attend appointments with the patient.

Other carers feel unable to raise questions about their own worries due to time with healthcare professionals being limited. Some carers said they would like to be asked what their worries are or simply how they are doing but feel invisible at appointments because the focus is all on the patient.

“I need information to be able to process how to pitch things to the children, to family and to myself. At the end of the day I need to manage expectations across everyone. It can be very difficult to do that when the information you’re getting yourself is limited.”

“I think what Myeloma UK does really well is it comes across as inclusive. It’s an acknowledgement that everybody is affected and just because we don’t have the illness doesn’t mean our lives are not just as much turned upside down.”
6% of carers who attend medical appointments with their relative or friend are asked how they are by the healthcare professional.

Some carers added that while they want to ask questions, the patient wants fewer details and therefore they do not want to interfere with these wishes. Others, however, were comfortable asking any question in front of the patient.

Those who did have the opportunity to speak with healthcare professionals found it beneficial.

50% of all carers in our research had never heard of a Carer’s Assessment.

Many of the carers in our research indicated that they would have liked more external support to deal with the practical and financial implications of caring.

While the process and terminology differs slightly around the UK, Carer’s Assessments are meant to be available to all carers, with the aim of assessing carers’ needs and entitlements for practical and financial support. However, half of all carers in our survey had never heard of an assessment for carers, and only 6% had an assessment.

Many participants reported that they did not want or need a Carer’s Assessment. However, of those who thought it would have been useful, almost all were unaware of what it was.

“Sometimes it’s like you’re invisible. Of course it’s all about the patient, but at the same time to have a little bit of support would be nice.”

“When my wife has gone in to see the consultant I’ve stood outside and had a chat with the specialist nurse and they’ve asked ‘is there anything you want to know or talk about.’ They’ve been really good and they give you as much time as you need as well.”
Barriers to receiving support

One third of carers in our survey said they do not access any support at all.

While for some caring is very much a ‘private matter’, most carers feel that at times they would like more support.

Several key themes arose in our research that may explain what the barriers are to accessing such support:

■ **Awareness of what support is available and how to access it**
  Many carers are not aware that support groups and other types of peer support are available, or that Myeloma UK has information and support services specifically for carers. Very few carers have heard of Carer’s Assessments and know what they were for.

■ **Not wanting to upset the patient or go against their wishes for information or support**
  Many carers put the patient’s desire for less information above their own information needs. Others explained that although they as a carer want more support (either informal or formal support) the patient does not want to accept it.

■ **Difficulty asking for help**
  Often carers expressed a wish to live life as normally as possible and that for this reason they find it a struggle to ask for or accept help.

■ **Reluctance to bother others**
  Many carers say they do not want to bother others, especially healthcare professionals, with their own questions and worries.

■ **Professionals not recognising carers’ needs**
  Carers often reported that although they are involved to a large extent in discussions about the patient’s myeloma and treatment, they feel their own information and support needs are not picked up on by healthcare professionals.

■ **Funding, accessibility and flexibility of support services**
  Some carers experience a struggle to get any support from statutory services such as counselling, social services support and access to GPs and hospital staff, citing funding and over-stretched services as a barrier.

“I was told I was suffering from depression and severe anxiety so I was given a phone ‘counselling’ session and told to go on an anti-anxiety course. I was unable to attend as I work part-time as a teacher and it was on one of my teaching days.

My second ‘phone call’ I missed as dad was in intensive care with pneumonia. I was left a message saying that I would be referred back to the GP. Complete waste of time!”
Conclusions and recommendations

Relatives and friends of myeloma patients take on considerable caring roles, and for many this involves significant life changes and challenges. Our findings are reflective of the academic literature on the psychosocial impact of caring for a person with cancer.

As a myeloma community working together we can and must ensure relatives and friends of myeloma patients have the information and support they need to deal with the impact of myeloma that they themselves experience and to support them in their caring roles.

Ensuring that carers get the support they need is both critically important and complex. Our research has confirmed that there are many challenges preventing carers from both seeking and accessing support for themselves.

The research has helped Myeloma UK better understand the barriers we need to tackle. It underlines the importance for us in continuing to develop, improve and extend the reach of our own services for carers. It also reinforces the need for us to further enhance our role in connecting carers and the myeloma professional community to ensure there is joined-up, comprehensive support in place for all carers to access when they need it.
What we are doing now

The findings from this research have directly informed our new and comprehensive Infopack for Carers of myeloma patients and we will continue to develop new information and services specifically to address the information and support needs of carers.

We are also using the findings of this report to call on the wider myeloma community to work with us and focus on the following key issues raised by our research:

1. Ensuring carers are provided with carer-relevant information and signposts to services they can access for further information and support.
2. Recognising and responding to individual carers’ needs for information and support as part of routine myeloma care.
3. Addressing the gaps in support felt in particular by carers at the time their relative or friend is diagnosed.
4. Improving awareness with carers of what support is available for them.
5. Supporting carers with a range of strategies and services to deal with the emotional impact of caring for someone with myeloma.
Myeloma UK has a wide range of information and support services for carers.

Our new *Infopack for carers of myeloma patients* is for anyone providing support and care to a myeloma patient. It provides you with information and practical tips to help to look after yourself and how to access the help and support you might need. Download your copy from [www.myeloma.org.uk](http://www.myeloma.org.uk) or request a pack on 0131 557 3332.

The Myeloma Infoline offers a confidential information and advice service to anyone affected by myeloma. More than half of all callers are relatives and friends of myeloma patients. Specialist information nurses can answer your questions, provide a listening ear and guide you to information and support.

Call free on **0800 980 3332** between 9am and 5pm Monday to Friday.

For full details of our services and information for patients and families visit [www.myeloma.org.uk](http://www.myeloma.org.uk)