

**When multiple myeloma (MM) returns or you need to consider your next treatment
It's time to focus on communicating effectively**




I'M NOT DONE SHARING

**A practical guide to effectively
communicating your
priorities to others**

Created with input from myeloma patients and care partners.

The information provided is for educational purposes only
and is not intended to replace discussions with a healthcare provider.

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It's time to talk about what matters most to you

When multiple myeloma (MM) has returned, or you need to consider your next treatment, communicating what matters most to you, in terms of disease management, lifestyle and family can be useful. It could help you find a care plan to suit you and help you live well with MM. You may already have taken the first step by finding what matters most to you. But remember, as your journey with MM continues, your top priorities may change.

If you are still working out what is important to you, please visit www.myelomaandme.co.uk. You will find useful tools that could help you define your priorities.

Once you have found what matters most to you, it is time to share this with your healthcare team and loved ones. This may help them understand why your priorities are important to you.











Open and honest discussion could help you build your confidence and help you live well with MM. It can also allow others to understand what you need to support your priorities.^[1-4]

Within this booklet, you'll find useful suggestions on how to have these conversations, to help your wellbeing with MM.

Speaking with a care partner

If you have a partner or loved one in your life, or others who want the best for you, they'll want you to let them know how you feel. This means sharing your priorities and why these things are so important to you. By doing this, you can work together to manage these priorities.

Tips for communicating effectively

-  **Decide how and when you want to talk**, either face to face or on the phone, when you are both feeling relaxed or motivated, in the morning or evening, weekday or weekend
-  **Explain why you have these priorities** and why they are important to you
-  **Outline any changes in your life or care that you think could help support your priorities**
-  **Choose a calm environment** where you won't be interrupted
-  **Take the list of priorities** you prepared and explain that you have carefully worked out what matters most to you
-  **Ask them if they have any questions and if they understand your priorities**
-  **If they need help to work out what matters most to them**, direct them to the 'Find what matters to you' booklet at www.myelomaandme.co.uk
-  **Try to be clear and calm in the way you speak** but bear in mind this may be a tricky time for both of you

You are not a burden to your loved one(s). They are there to listen and help you. Having these open discussions could help you both and allow you to manage these priorities, together.

Working through potential disagreements

Living with MM can be hard. Whether you're going through this yourself, or caring for someone who is, you may not always see eye to eye. Illness may bring some families together, but may create disagreements and problems in other ways.^[4]

Tips for working through challenges^[4]



Accept that different people may have different opinions and ways of coping



Sometimes you may not feel ready to talk, and that's okay. Let your care partner(s) know that now isn't the right time and you would like to talk to them later about your MM. This could help your care partner(s) understand how you feel and that these conversations can take time



Realise that some people may be trying to help, even if it doesn't seem like it at the time



If there is an issue, try to address it quickly before it gets worse



Remember that you are working towards the same goal



It is important you both work together to try to find ways of sharing everyday tasks. Try and do this in a way that makes everyone happy



If you and your care partner(s) are still finding it difficult to resolve an issue, consider seeking professional relationship help.

Sharing your priorities with a partner could help you both find a care plan that suits you, together



Speaking with your healthcare team

Once you've found what really matters to you, it's time to discuss these priorities with your healthcare team. You can work together to find a care plan to suit you. This in turn could help you live well with MM.

Getting the conversation started

Before you go in, don't forget to take your list of priorities with you and highlight why they matter to you. Early planning could help build your confidence in having this conversation and help you get the most out of life with MM. Think about how your priorities may affect what treatment you're offered by your doctor.

Try to be upfront and clear about your thoughts and ask questions if you need more information or need the doctor to repeat something. Remember to keep calm even during any tricky parts of the conversation. This could help you both to reach an agreement.



Here is some inspiration to help you get started

Do you have any questions about your family priorities?

Do you have any questions about your disease management priorities?

Do you have any questions about your lifestyle priorities?

Consider taking notes or asking if you can record your appointment, for example on your phone. This way, you can go back to the answers afterwards.

At www.myelomaandme.co.uk you will find practical techniques to help you start the conversation with your healthcare team. There are also testimonials from others with MM, and resources to help you live well with MM.

Preparing for your appointment

During your appointment, your doctor might ask you questions. It could help prepare you for an effective conversation about what matters most, by thinking about what your answers might be beforehand. Ask your doctor if you can bring a care partner for support, even if it is a virtual appointment.

Questions your doctor might ask

Have your symptoms changed since I last saw you?

How do you feel in your daily life?

Are there any tasks or hobbies you can no longer do?

How do you cope with your treatment?

Has your treatment caused any side effects?

How are you coping with your treatment plan?

Has your appetite changed?

Have you noticed a change in weight?

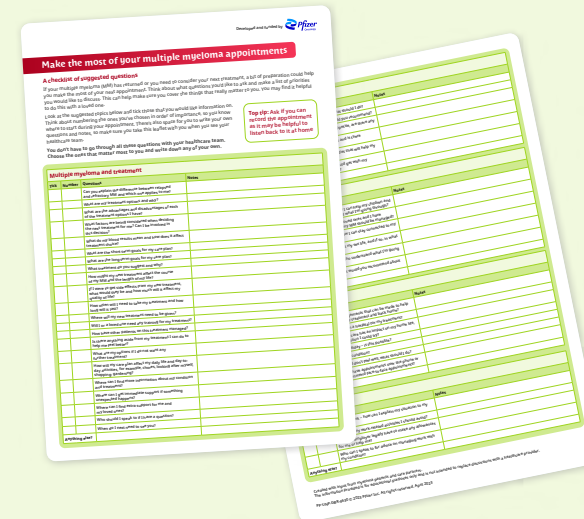
Are you supported by loved ones or care partner(s)?

You might like to take a list of your priorities to your appointments. This could remind you to speak about what your options might be and how they fit in with what matters to you in your daily life.

Need help preparing for your next appointment?

Want to prepare for your next appointment?

Visit www.myelomaandme.co.uk.



Download a printable list including further questions you may want to ask your healthcare team at your next visit.

Create a list of questions you would like to ask your healthcare team at your next visit, such as “What could I expect from this treatment?” “Is there anything else I could be doing to take care of myself?” Write down the answers so you can look back at them after the appointment.



I'M NOT DONE LIVING WELL

Have you tried talking about your priorities? Maybe try writing them down first. This gives you a clear way to speak through them with a care partner or your healthcare team.

www.myelomaandme.co.uk

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If you have any other questions, please speak with your healthcare team.

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