

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




**I'M NOT DONE
DOING WHAT I LOVE**

**A practical guide to uncovering
your priorities and improving
your wellbeing with MM**

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.

A programme developed by  **Pfizer**
Oncology

Focus on your priorities

When multiple myeloma (MM) has returned or you need to consider your next treatment, identifying what matters most to you could be the first step towards working with your healthcare team to find a disease management plan that suits your needs.



Everyone is different and we all have our own needs and priorities. But putting yourself first and figuring out what truly matters to you isn't always as easy as it sounds. This booklet has been written to help you.

You'll find suggestions of things you might like to consider when thinking about what matters, including:

- ▶ **Examples of what finding your priorities could mean for you**
- ▶ **Three methods you can use to find what matters most to you**

Focusing on your priorities could improve your wellbeing by feeling in control of your MM.

What could your priorities look like?

What matters to one person might not be the same for someone else. Look at what others consider important below and how they were able to work this out for themselves. You'll find more details on the next pages to help get you thinking about what matters most to you.

Having a list of things that are important to you is helpful. If it's really long, try to find ways of cutting it down to find what matters most.

What matters most to you may be different to the next person. Try figuring out what your priorities are and follow that.

Try thinking about what in your daily routine brings you joy. This could be a good place to start in finding what things are important to you.

***What really lifts your spirits?
The answer may help you
uncover what matters
most to you***



Three ways to help you find what matters most to you

Thinking about the things that are most important to you may come easily or may seem hard to do at first. If you don't know where to start, here are three different methods that could help you find what really matters to you:



Answer questions to reveal your priorities



Create your own priorities and rank them in order of importance



Use pair-wise ordering to narrow down your priorities

Working through these methods can help you define what is not as important to you, so you can focus on what really matters.

If you are still unsure about any of these methods, consider asking your care partner for help.

You will find examples of how to use these methods to help you on the following pages, or visit www.myelomaandme.co.uk for even more tips, advice and help finding your priorities.

Use one or more of these methods to reveal what matters to you



What are your family priorities?

Think about what is most important to you with your family and friends and how these priorities could affect your care plan. There is space for you to write your thoughts down at the end of this booklet.

Things you might like to consider:

Do you have any commitments that require you to be at home, for example, looking after children or grandchildren?

Do you have responsibility for any people or pets?

Are there any activities you love doing with family or friends, for example, cooking meals?

Is keeping the romance alive in a relationship important to you?

Do you have any regular commitments that are important to keep?

Is spending more time with loved ones a priority for you?

Is taking the pressure off your family important to you?

Think about the parts of family life that matter most to you





Identifying your priorities may enable you to stay focused on what you value most

What are your disease management priorities?

Think about what is most important to you with disease management and how these priorities could affect your care plan. There is space for you to write your thoughts down at the end of this booklet.

Things you might like to consider:

Does it matter where your treatment will be given?

Is it important to have someone help you with your treatment?

Are there specific side effects you want to avoid?

Is how long a treatment takes to administer important to you?

Does it matter if your treatment requires travel to a specialist centre?

Does it matter to you how often the treatment is taken?

Is it important that managing your treatment and side effects don't increase the burden on you or your loved ones?

Is how much time you spend in the hospital for treatment important to you?

Is it more important to maximise your quality of life or life expectancy?

Think about the parts of disease management that matter most to you

What are your lifestyle priorities?

Think about what is most important to you in your daily life and any activities, hobbies or goals you want to prioritise. There is space for you to write your thoughts down at the end of this booklet.

Things you might like to consider:

Is keeping active important to you? Is there a type of exercise you want to continue doing?

Is staying social a priority for you?

Do you have a hobby that you love, for example, playing a musical instrument or craft?

Do day trips to galleries, theatre, or other ways of getting time off matter to you?

Is going on holiday a priority for you?

Is work something that keeps you going?

Is it important for you to be able to see friends in person rather than calling, texting or social media?

Think about the parts of your daily life that matter most to you



Answer questions to reveal your priorities



Q&A
method

If you're finding it tricky to come up with your own list, answer the following questions. There may be more than one answer to each question, so try to record as many answers as you can. There is space for you to write at the end of this booklet.

What do you most look forward to every day?

What do you miss when you can't do it?

If you close your eyes and imagine pure happiness, what do you see?

Is there an activity you want to continue doing?

Is there something you've never done that you would love to do?

Are there any tasks that you do not want to do?

What are things you did this week that you would not miss if you stopped?

Can you think of any other questions to ask?
If this didn't work for you, try one of the other methods of working out what matters most to you



Pair-wise ordering example

Write your priorities in the left-hand column and then in the same order in the top row as shown in the grid below.

- ▶ Compare each priority and give one point to the option you prefer and a zero for the other
- ▶ If you really can't decide between two options, give a half point to each
- ▶ Keep comparing the priorities against each other until you have a final score for each one

Priorities vs each other	Scores						Order [highest score = most important]
	Gardening	Pets	Time with family	Independence	Limiting travel for care	Total score	
Gardening		½	0	1	0	1 ½	Joint 3
Pets	½		0	1	0	1 ½	Joint 3
Time with family	1	1		1	1	4	1
Independence	0	0	0		0	0	5
Limiting travel for care	1	1	0	1		3	2

Compare each topic with another and give it a score 0, ½ or 1. Here, time with family is preferred over gardening

Most important

Least important

Create your own pair-wise ordering

Priorities vs each other	Scores					Total score	Order [highest score = most important]
			2				

Remember, the three topics with the highest scores are your top three priorities. The topic with the highest score is your number one priority.

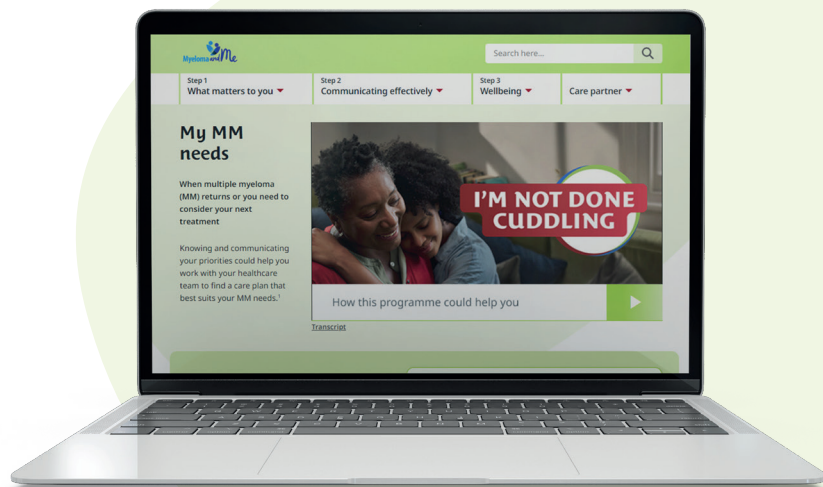
- 1 Write down one thing that matters to you in each of these five spaces
- 2 Compare each of your topics against each other in pairs and score them 1 [preferred], 0 [not preferred], or ½ each if you really can't decide
- 3 Then, add up your scores
- 4 Finally, order your topics - remember that your highest score in the total scores column is your No.1 priority

Congratulations

Working out what truly matters to each one of us is not always easy, so well done for working through this booklet! You've already taken the first step to help you develop a care plan including what you value most.

Remember that your priorities may change as your situation does. You may want to repeat these exercises from time to time. Make sure your priorities are still the same and update them if they've changed.

You'll also find a handy pre-appointment checklist to print out at www.myelomaandme.co.uk. It has different topics that could help you decide what questions you want to ask your healthcare team about the priorities you've identified here.

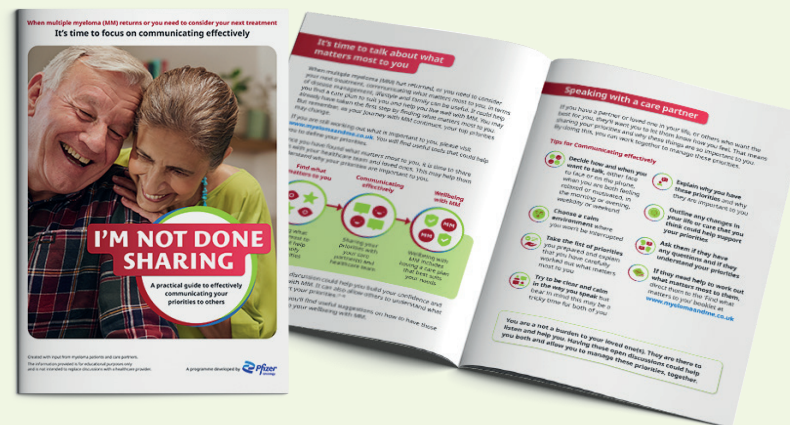


www.myelomaandme.co.uk

Sharing your priorities with others

Once you've decided what matters most to you, you're ready to take the next step and share these with your loved ones, care partner(s) and healthcare team. Positive and effective talks about your priorities could help others understand why they are important. This can help them know how they can support you to live well with MM.

The 'Communicating effectively' booklet will help and support you to start these conversations.



Download the booklet yourself at www.myelomaandme.co.uk.

At www.myelomaandme.co.uk you will find useful tools, experiences of others just like you, and guidance on what you could do to improve your wellbeing with MM.



**I'M NOT DONE
LIVING WELL**

Take the time to review your list of priorities. Numbering them in order could help you see what truly matters and the things to concentrate on.

www.myelomaandme.co.uk

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A programme developed by 