



TIME
KEEPER

janssen 

Can we talk about time?

Discussion Guide for Patients Living with Multiple Myeloma

Introduction to this guide

This guide has been developed for use by patients living with Multiple Myeloma to aid starting a conversation around the concept of time and quality of life with their healthcare team, including treating physicians and specialist nurses. It can be used ahead of consultations as a thought starter and to prepare for discussions – which may be particularly valuable for virtual consultations that have become increasingly common. Alternatively, it can be used during consultations if preferred.

Expressing the importance of time when living with multiple myeloma

Waiting. We spend so much of our lives doing it.

You may wait to finish school, climb the career ladder, travel the world, meet the one and start a family, or finally buy your dream property... then retire and freely enjoy your time. But a multiple myeloma (MM) diagnosis means you need to keep on waiting – to see the doctor, then the specialist, to sit in waiting rooms and wait for treatment.

When you have MM, waiting can become your life, and time becomes even more precious.

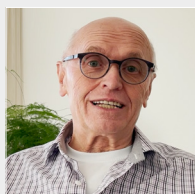
It doesn't have to be this way.

You can speak to your doctor about the impact MM has on your plans for the future, the personal choices that may help you make more of your time, your experiences or expectations for treatment and which treatment option may be best for you.



"If you sit around thinking about how you have cancer, it will make you a prisoner. It doesn't help anyone. Not your family, your friends, or yourself. It really makes life easier if you can say 'Okay, I'm suffering from cancer but this doesn't prevent me from doing the things I used to do or even doing things that are new for me.'"

– Norbert Schmidt, living with MM.



'Your perception of time changes. You start appreciating minutes, not just your vacation or holiday but every minute of joy that you can get from your life.'

– Tatiana Serova, living with MM



Following a diagnosis of MM, your focus may be on dealing with the practicalities of treatment as well as coming to terms with what the diagnosis means to you and your loved ones. As the weeks pass, living with MM can begin to impact on your time and quality of life and yet when changes are gradual, they can often be overlooked or be difficult to place a finger on how they are affecting you.

Below are some questions that you can use as thought starters to help you consider how you spend your time before compared with after a MM diagnosis. There is space to write your thoughts below each question.

Your responses should be personal to you and can be used as a framework to help you discuss time, and what you can do to make the most of your time, with your doctor during a virtual or face-to-face consultation.



Consider how you spend your time now vs before your diagnosis of MM.
What is taking up your time now that didn't before?

How is this disease and your treatment impacting your quality of life?

What kinds of activities, including hobbies and interests, can you no longer seem to find the time and/or energy for?

How has the COVID-19 pandemic affected the way you spend your time and your quality of life since your MM diagnosis?

If you could spend your time in a different way, what would you like to do more of?



Finding more time for life – an innovation for people living with MM

Research shows that the older we get, the less likely we are to encounter new information. Our brains also don't spend much time processing familiar information. Together this makes our perception of time change – it appears to speed up.¹

But, when we do new activities, time seems to last longer. Even a short trip can feel like a lifetime compared to a week at home filled with routine activities and chores. Why? Because new impressions take longer for the brain to process than routine ones – making time feel elongated.¹

The innovative Time Keeper clock uses this concept to encourage patients to explore time differently, helping to ease the weight of a diagnosis. Time Keeper helps empower people living with MM to discover new ways of creating time, by providing inspiration to try novel experiences and encouraging the exploration of new skills, places and people.

Try it yourself, experience
novel activities and discover
new ways to enjoy your time.



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References

- 1 David Eagleman. The Science of Time Perception: Stop It Slipping Away by Doing New Things. Available at: <https://buffer.com/resources/the-science-of-time-perception-how-to-make-your-days-longer/> Last accessed: April 2021