



WHAT IS IMPORTANT  
TO PEOPLE OF WORKING AGE  
LIVING WITH MYELOMA  
IN EUROPE?

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|   |    |
|---|----|
| <b>FOREWORD FROM BARBARA LEONARDI</b> .....   | 04 |
| <b>ABOUT MYELOMA</b> .....  | 05 |
| <b>YOUNGER PEOPLE WITH MYELOMA</b> .....  | 05 |
| <b>WHAT THIS RESEARCH AIMED TO DO</b> .....   | 05 |
| <b>HOW THIS RESEARCH WAS CARRIED OUT</b> .....  | 06 |
| Phase 1 .....   | 06 |
| Phase 2 .....   | 06 |
| <b>RESULTS FROM PHASE 1: THE LITERATURE REVIEW</b> .....  | 06 |
| 1. Dealing with symptoms and treatments while working can be a considerable burden .....        | 06 |
| 2. The impact of illness and treatment can impact relationships .....                           | 07 |
| 3. Continuing to work with adjusted patterns and responsibilities can bring normalcy .....      | 07 |
| 4. The financial impact of myeloma for younger age patients can be particularly difficult ..... | 07 |
| <b>RESULTS FROM PHASE 2: THE INTERVIEWS</b> .....   | 08 |
| 1. Systems, structures and services .....   | 08 |
| 2. Reconciling illness with work .....  | 09 |
| 3. Living with a chronic, incurable disease .....   | 10 |
| <b>RECOMMENDATIONS FROM THIS WORK</b> .....   | 12 |
| Practice .....  | 12 |
| Policy .....  | 13 |
| Research .....  | 14 |
| <b>FURTHER DETAILS ON THIS WORK</b> .....   | 15 |
| <b>PATIENT SUPPORT</b> .....  | 15 |
| <b>ACKNOWLEDGEMENTS</b> .....   | 15 |
| <b>REFERENCES</b> .....   | 16 |

# INDEX



## FOREWORD FROM BARBARA LEONARDI

### Barbara Leonardi

Carita Foundation and MPE board member

Who are myeloma patients? What are their everyday struggles? How do they cope? There are many preconceptions surrounding these questions. For example, multiple myeloma is often considered an illness of older age, however 37% of patients are under the age of 65 and 10% are under the age of 50. This means many patients are working at the time of diagnosis and when they undergo treatment. Still, the issues and concerns of younger patients seem invisible, even though the group is not that small.

But why is it important to understand the perspectives of younger patients? There are several dimensions to this question that our report explores. Let me highlight the key two. Firstly, there's the psychological and emotional burden. Hearing the words "incurable" and "lifelong treatment" while caring for growing children and elderly parents, all while at the height of one's professional career, requires enormous readjustments in both personal and work life. Secondly, there's the medical aspect. Clinicians and researchers are more accustomed to treating and interacting with elderly patients. It is challenging to design a myeloma pathway that spans decades and includes a multitude of anti-myeloma treatment lines, let alone anticipate the outcome.

Our study examines critical aspects such as financial toxicity, the burden of symptoms combined with work, negative work experiences, and stigma. By shedding light on these issues, we aim to enhance the support systems for myeloma patients and their carers, ultimately improving their quality of life and their journey with myeloma.

The report you are about to read was created for and with the help of patients living with myeloma and their carers. Its primary aim is to understand how younger patients, specifically those aged 65 and younger, cope with the disease, treatment, and daily life. The findings are based on surveys conducted with patients in the Czech Republic, Germany, and Poland who have undergone at least one line of treatment for myeloma.

We need to remember that behind every statistic there are real patients. It is essential to see the people behind the numbers. I believe that this project and the report will accelerate our understanding of younger patients' perspectives on what it is like to live with myeloma and what it is like to treat young myeloma patients. It is important to give a voice to the minority that turns out to be, well, not so small.

## ABOUT MYELOMA

Myeloma (also known as multiple myeloma) is a rare blood cancer that forms in the bone marrow and affects around 50,000 new patients in Europe each year. Although this form of cancer has been traditionally associated with poor survival outcomes, new treatment options such as high-dose therapy and autologous stem cell transplantation significantly lengthen both survival and life quality of those affected. However, myeloma is still incurable, and most people will relapse and/or no longer respond to treatment, with the disease becoming more aggressive and drug-resistant over time, and with shorter response intervals. The impact on people's lives can be considerable with treatments extending for years, with a high symptom burden such as pain, fatigue and anxiety, impacting quality of life<sup>1-3</sup>.

## YOUNGER PEOPLE WITH MYELOMA

The median age of diagnosis for myeloma is 66-70 years, with 37% of patients under 65<sup>4</sup>. Recent estimates suggest that around one in every 10 new cases are in patients younger than 50 years old<sup>5</sup>. This means that many patients are of working age<sup>6,4</sup>. The combination of illness, treatment, work and life-cycle transitions occurring in working age adults, present specific stressors. These impacts require better understanding to inform treatment decision-making, employer support and the patient's engagement in meaningful activity.

## WHAT THIS RESEARCH AIMED TO DO

There has been limited focus in previous research on working age adults with myeloma. Myeloma Patients Europe commissioned the University of Stirling, UK to identify what the unmet needs are of this specific group of myeloma patients. This research was developed to address the gap in knowledge and to understand more about the particular impacts myeloma has on working age people, their families, work and lives. This research aimed to describe how working age patients and their families navigate life, employment and other important activities when affected by ongoing myeloma treatments, and the burden of symptoms, side effects and illness trajectory. Through identifying different experiences and highlighting country-specific strengths and shortages of national health systems, the research aimed to inform future policy, practice and research.

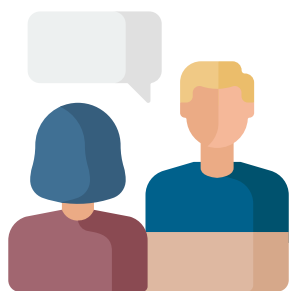
## HOW THIS RESEARCH WAS CARRIED OUT

This study involved two phases:



### Phase 1

Phase one was a systematic review of published qualitative literature. This involved synthesising existing data and learnings about what it's like for working age patients and their families to develop new understandings and theories<sup>7</sup>.



### Phase 2

Phase two involved interviewing working age myeloma patients and family members. Interviewees were recruited from three countries sharing borders; Czech Republic, Germany and Poland. These countries were chosen to allow for diversity in socio-economic context and purposively included two less researched Eastern European countries to highlight the systemic, social and cultural factors shaping people's experiences.

## RESULTS FROM PHASE 1: THE LITERATURE REVIEW

The systematic review focused on working age adults to understand the impact of myeloma on their paid and unpaid commitments. No date limitations were set, and the review included research papers published in any language. In total, 34 peer-reviewed articles were included in the evidence synthesis. When these articles were synthesised, there were four core findings:

### 1. Dealing with symptoms and treatments while working can be a considerable burden

In the existing literature, myeloma patients reported changes to attention, focus and cognition as particularly difficult to manage while working. These changes were often how people identified when they should step back from work. Studies reported the difficulties people faced in balancing the demands of treatment, side effects and symptoms. Stigma in the workplace was experienced by some and this experience could lead to a feeling of 'loss of power in the workplace' and feelings of inadequacy. Self-administering medication and treatment regimes that avoid hospital are helpful in supporting work attendance. The same goes for proactive and reactive adaptations and accommodations by employers to facilitate working.

## 2. The impact of illness and treatment can impact relationships

The literature reported relationships being affected by myeloma treatment and illness. For some myeloma patients who disengaged from work, there was loneliness and isolation. The income lost from work changes could also result in a greater reliance on family for financial support, which further impacted relationships. A renegotiation of roles and responsibilities within families may be needed around childcare and domestic chores as the severity of symptoms change over time. These shifts in roles and responsibilities may bring with them guilt or frustration. Conversely, some data from the literature showed that relationships may be enhanced, with more prioritising of family and through forming and deepening bonds that can occur with sharing of experiences.

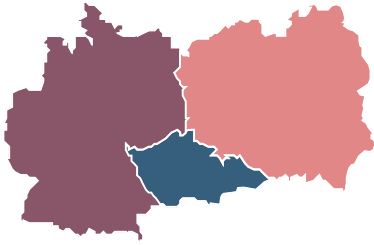
## 3. Continuing to work with adjusted patterns and responsibilities can bring normalcy

For some people with myeloma, work is an important part of their identity, providing respite from illness-saturated lives. Serious illness could destabilise anticipated futures and disrupt people's ability to plan ahead, including for their retirement. Engagement with work was intimately connected with financial security, and working before, during and after treatment may be through choice or necessity. Work can be an essential component of identity, used as a coping mechanism to distract, and be a necessity to maintain income or health insurance benefits.

## 4. The financial impact of myeloma for younger age patients can be particularly difficult

The existing literature suggested that myeloma patients with young children and those further from retirement fared differently to those closer to retirement. There were different decisions to make about continuing or ceasing work. Younger age myeloma patients may have to step back from work or change their work commitments at a time when they might expect to be in their most productive working years. Myeloma patients accessing treatment without co-pays, deductions or employer insurance experienced fewer ramifications with their employment and income. Those in a more financially secure state were able to determine their priorities and rethink work in a way that people in a less secure position were unable to do. Women living alone were especially at risk of financial toxicity.

## RESULTS FROM PHASE 2: THE INTERVIEWS



A total of 36 working age adults living with myeloma and three family members were interviewed from Czech Republic, Germany and Poland. People were eligible to take part if they had received at least one line of treatment. Interviews were carried out via video conference calls between May and October 2022 taking on average 57 minutes. Analysis of the interview data showed three main themes:

### 1. Systems, structures and services

Most treatments in all three countries were covered by basic State support. However, feelings about treatment were not equal across all sites, with greater confidence in services in Czech Republic and Germany than in Poland.



“I think it's one of the best systems in the world (...) I am very lucky that I am born in Germany and living in Germany and have (...) advantages to have this health system. Because I meet a lot of people in Vienna, they come from Ukraine or Poland or Romania, Bulgaria. They have no maintenance treatment, for example.”

German patient, 34 y/o male



“What's really rubbish is the access to drugs here in Poland, because the country we have so close like Czech Republic, or even ... Romania, it turns out that the situation there is better (...). What's more, Czech Republic, which is not richer than Poland, and not to even mention Romania, they have these opportunities.”

Polish patient, 57 y/o female



“One thing that's absurd in the Polish system, I am not entitled to the sanatorium [State funded rehabilitation centres]– I can only go to a rehabilitation retreat for which I pay myself. You can apply for the sanatorium only three years after the disease has been cured. So, three years after I've been buried in the coffin, they will dig me out and take me to sanatorium, well that's a travesty. Because these are the regulations from the 1950s, and the doctor is helpless. And the patient needs as much help as possible, especially when he has fractures that need physiotherapy, those three weeks would be, for one thing, a reprieve for the family, a rest for the family.”

Polish patient, 65 y/o male



Across countries, patients felt varying levels of responsibility in navigating complex health and State systems to gain the treatment and support they required. This added considerable burden to their already demanding lives. Despite myeloma being recognised as incurable and having complex symptoms and complications, discussions about palliative care were largely missing from clinical communication. Instead, doctors focused on active treatment and short-term goals. Patients gained their insights into supportive and palliative care from the internet or patient support groups. These informal networks and organisations provided a wide range of support and information to patients and families.

## 2. Reconciling illness with work

The degree of work engagement was informed by patients' symptom burden, treatment needs, State financial aid and family/financial obligations.



**"I came back part-time. And after one month I already knew that my body could not cope (...) Well, so the decision had to be made, well, whether it's work, or are we fighting for this life that was saved, so not to ruin all this."**

Polish patient, 47 y/o female

Many did not conceptualise their status as involving 'return to work' as they had continued to be engaged with their jobs throughout. For those with changed incomes, financial pressure temporarily or permanently changed family/relationship dynamics. For some, remote work enabled them to manage treatments/side effects and their job, while avoiding infection. Workplace support was often high, though some interviewees indicated feeling at risk of discrimination if they disclosed their illness to employers. They also expressed a lack of trust in employers abiding by employment protection regulations.



**"I did inform my employer (...) and he's been very understanding of it. He gave me all the time needed for going to therapy, for doing my health checks, so formally I was still working (...). But I did get my time to do all my health check-ups (...). Then in December I had to do the stem cell treatment; I took six months' sick pay (...) I am back at work since July on a full-time basis, but in agreement with my employer that I will still need extra time for my treatments and therapies."**

German patient, 49 y/o male



“One [firm made a job offer] and when they learnt I have this disease, they told me not to join.”

Polish patient, 38 y/o male



“I rather would not tell them. I made an online check whether to tell or not to tell. The result for me was rather not to tell the employers. [In my] certificate of disability, [myeloma specifically] is not mentioned.”

German patient, 53 y/o male

### 3. Living with a chronic, incurable disease

Patients and relatives had to engage in an enduring task of negotiating life with this chronic and incurable disease.



“Before the illness I was just someone who couldn't say no, and I was putting my best to everything on 230 percent (...) So I changed my view on a lot of things. I just say no when I don't feel up to something. I listen to my body. If my body is telling me it's too much, I don't do it. I just respect myself a lot more.”

Czech patient, 47 y/o female

Managing the uncertainty of disease progression, lifespan and the COVID-19 pandemic all involved considerable effort. A desire to prioritise enjoying life was somewhat curbed by the pandemic, which forced isolation and constrained social activities. As myeloma affected the whole family dynamic, there was considerable discussion about the reorganisation of existing family life.



“My [children] suffered a lot. (...) they took care of their sick mother for two years. So, [my child's] education process was delayed for three years at least. (...) And my children will be burdened with it too – fortunately one has already changed her surname, yes [laugh].”

Polish patient, 58 y/o female

Changes to a wide range of relationships were observed in the respondents' accounts. This included parents, children, partners, siblings and friends.



“So, when I first was diagnosed (...) my children were quite young (...) so they were not understanding it in the same way that they can understand it today. They were mostly worried about their dad, because they heard the word cancer, so they were worried that they may lose their dad, but then throughout the first year and afterwards they realised that it doesn't have to be so grim; it can have a better progress. So, when I adapted, I was able to continue living a normal life in relationship to my family, to the wider family, my children.”

Czech patient, 51 y/o male

Some relationships broke down, and others shifted from romantic to instrumental caregiving.



“I have a good friend (...) I've known her almost 30 years. I was going out with her somewhere, maybe in a disco or concerts or stuff like that. She can't understand that I can't do this anymore; she always thinks I'm still healthy. She asks me, 'Oh, you don't want to go with me there?' She never visits me in the hospital. I don't know! (...) She can't accept me, my illness, my sickness.”

German patient, 59 y/o male



“Right now, to be honest, I don't know if we can ever make up for it. Maybe one of the reasons was also that I expected more support from my husband during my difficult times, these difficult months – I didn't have that much support, so that was it. And also, I think that my behaviour, when he was trying to hug me, or caress me (...) I was pushing him away. (...) Because I had so many thoughts in my head (...), I will die anyway, and soon, and it will be more difficult for him then [chuckle].”

Polish patient, 58 y/o female

## RECOMMENDATIONS FROM THIS WORK



### PRACTICE

- Within the hospital setting, more consistent and empathic conversations by clinicians are required regarding supportive and palliative care. Patients are aware of the life-limiting nature of the disease and ensuring patients understand that there will be continued supportive care even when treatments no longer work should be incorporated into transparent discussions and shared decision-making. Palliative care does not preclude hope but holds the importance of enhancing bio-psych-social-spiritual quality-of-life at its centre.
- Clinical discussions around treatment decision-making should take into account patients' attitudes/approach to work, type of work engaged in, and other activities considered important to them. This shared decision-making approach will enable patients to achieve better quality-of-life and avoid financial toxicity, or dependence on family and State. The approach will require treating teams, patients and employers to work more closely and explicitly around the treatment goals and choices. This may, for example, lead to more flexible approaches to treatment modalities, or work routine, to reduce the impact on the patient. Such an approach may require involvement of health insurance providers, and hence involvement of additional systems and organisations.
- Interventions by employers can play an important role in supporting people to continue working. Stigma is a modifiable variable which can aid people's ability to successfully engage in work. Addressing stigma and discrimination together would improve patients' lives and reduce concerns that disclosing their diagnosis would lead to unfavourable treatment in the workplace. Clinical or multi-disciplinary teams for the treatment of myeloma patients should include access to advice on holistic cancer care issues, returning to work and work-place issues (such as occupational health, specialists trained on this topic), nurse specialists and palliative care nurses/specialists.
- Better support for people's interpersonal relationships is required, recognising the risk of relationship strain, breakdown and sexual dysfunction. Systemic family/couples' therapy would be advantageous in supporting the complex and chronic relational changes faced by people living with myeloma.



## POLICY

- Across all three countries, reviewing and improving the process of acquiring disability status/benefits would be advantageous. Presently, these processes are not appropriate for a relapsing/remitting incurable illness such as myeloma. During remission, patients' disability classification is often lowered, and consequently they not only lose some of the financial assistance, but also have to undergo repeated disability reassessments. Given the disease trajectory and symptom profile, the continued immersion in bureaucratic processes to maintain disability is unduly burdensome.
- Legal protections and better enforcement of employer policies to accommodate patients' limitations in the workplace would be beneficial. Such adaptations would alleviate feelings of employee inadequacy and prevent internalising stigma, which can impair their performance and/or willingness to remain in employment. Workplace adjustments such as remote or flexible working (whenever possible) could help patients manage their symptoms and mitigate fears of potential job loss, leading to worsening financial toxicity and relational strain. Flexible working would also help patients attend hospital appointments or manage days when symptom burden is high. For those in more physically demanding jobs that cannot be carried out remotely, re-training options could be provided.
- Greater cooperation between doctors and patient organisations would unburden the patient from activism, engagement and diplomacy in navigating often complicated relations between the State, private and charity sectors.
- In Poland, outdated regulations prevent myeloma patients from using sanatoriums (State funded rehabilitation). As many patients would benefit from such treatments, a change in classifying myeloma would be needed, with more understanding of patients' rehabilitation needs.
- EU and national cancer plans should set out optimum standards for workforce and multi-disciplinary teams to ensure patients - particularly those of working ages - are able to access advice and support on returning to work, finances and holistic issues associated with their cancer.
- Cancer/health policy and regulations should consider the needs of people who have incurable, relapsing and remitting, cancers. Specific attention should include protection and support where patients and unpaid carers may leave and return to work a number of times, as their needs will differ across the trajectory of the illness and change over time.



## RESEARCH

- There is insufficient insight into how relatives, friends and colleagues influence and inform treatment decision-making. In working age adults, the influence of both employers and colleagues requires further examination to understand the context and consequences of such decision-making.
- Research could help develop a greater understanding of how identity is shaped by employers, colleagues and customers. Further, examining such relational networks could aid strategies that seek to improve awareness of myeloma in the community. While myeloma remains a rare disease, there is great capacity for employees to share knowledge and understanding of this cancer impacting their own identity as well as colleagues' insights into illness.
- The unmet needs of unpaid carers/family members are an under-researched area. In the absence of primary research data, practice and policy changes risk being based on patient perspectives, rather than carers'/relatives' views and experiences.
- There remain considerable deficits in understanding how actions, such as combining households with parents/adult children to manage the financial impact of myeloma on income, are planned and experienced in the short and long term.
- Future research should aim for less homogenous samples than those identified in the literature review. Dissemination should routinely report participant ages with data extracts. Such transparency in study design and reporting will facilitate greater insights into the nuances of adults living with myeloma, including the ability to focus on those with particular characteristics, such as working age.

## FURTHER DETAILS ON THIS WORK

Forbat L. Multiple myeloma in people of working age in Czech Republic, Germany, and Poland: findings from a qualitative interview study. *Journal of Cancer Survivorship* (2023). <https://doi.org/10.1007/s11764-023-01510-1>

Forbat L., Sedgley T., Bellussi L. Multiple myeloma in people of working age: a systematic review and evidence synthesis of experiences of paid and unpaid work. *European Journal of Cancer Care* (2023). <https://doi.org/10.1155/2023/6292479>

## PATIENT SUPPORT

If you need support as a working age myeloma patient, please join MPE's [European Young Myeloma Patients Group](#) For local support, you can find information about member organisations [here](#).



Poland

[www.fundacijacarita.pl](http://www.fundacijacarita.pl)  
<https://www.szpiczak.com.pl/>  
<https://kierunekzdrowie.org>



Germany

<https://www.myelom.org>  
[www.leukaemie-hilfe.de](http://www.leukaemie-hilfe.de)  
<http://www.myelom.net/>  
<https://myelom.online>



Czech Republic

<https://www.mnohocetnymyelom.cz>

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