A patient-centred approach to multiple myeloma
The people-centred approach of the European Commission’s flagship Beating Cancer plan may be pivotal in understanding and treating patients of multiple myeloma.

Despite substantial improvements in multiple myeloma patients’ outcomes, most people living with this incurable blood cancer experience relapses as the disease develops resistance to therapies.

The findings of a qualitative study show that the most important treatment characteristics for myeloma patients across Europe are those which target life expectancy, life-threatening side effects, treatment response, nerve or bone problems, thinking problems, and reduced energy.

In this European Special report, the EURACTIV network explores the care pathway of myeloma patients across Europe as well as the latest innovation in terms of therapies.

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Multiple myeloma patients face late diagnosis, unequal access to therapies

By Gerardo Fortuna | euractiv.com

 Delayed diagnosis and inequalities in access to treatments across the EU are among the main challenges in fighting multiple myeloma, an incurable and rare form of blood cancer.

Roughly 50,000 people in Europe are diagnosed yearly with multiple myeloma – a rare cancer of plasma cells found in the bone marrow.

Plasma cells are tasked with making antibodies to recognise and fight germs, such as viruses or bacteria. With multiple myeloma, however, the division of plasma cells is out of control and immature plasma cells start multiplying and filling up the bone marrow, becoming cancerous.

Multiple myeloma, also known as Kahler’s disease, does not have any effective cure – the disease develops resistance to almost all therapeutic approaches.
Multiple myeloma, also known as Kahler's disease, does not have any effective cure - the disease develops resistance to almost all therapeutic approaches. This aspect distinguishes the disease’s pathway and its pathology with a slow progression and recurrences, further reducing the quality of life of patients.

The recent focus on cancer by the European Commission culminated in its flagship Europe’s Beating Cancer Plan, which featured 10 flagship initiatives that address the entire disease pathway in a ‘people-centred’ approach.

One of the main features of the plan is the strong reliance on what has been described in the Plan as “a whole-of-society effort that follows the ‘Health in All Policies’ approach”.

“Cancer care is no longer the responsibility of the health sector alone. It requires engagement and buying from a wide range of sectors and stakeholders,” the Plan itself reads.

“Europe is putting lots of effort into trying to increase education, increased training, and increase awareness of myeloma,” said Charlotte Pawlyn, haematologist consultant at the Royal Marsden in London, in an event on the occasion of the first European Myeloma Day.

“But I think we also have to be aware that it remains a rare disease,” she added referring to the importance of other broader approaches that go beyond reliance on just doctors.

**Early diagnosis and access: The main problems**

There are varying unmet needs of myeloma patients across European countries, Kate Morgan, co-CEO of Myeloma Patients Europe (MPE) explained to EURACTIV.

“However, early diagnosis and inequalities in access to myeloma treatment are two elements we identify as main, overarching problems,” she added.

A report drafted by MPE showed that myeloma diagnosis can take over five months and require more than four medical consultations with more than three different specialists.

It is common that many myeloma patients have been initially misdiagnosed with more common conditions before finally being referred to a haematology department and having a diagnosis confirmed.

Myeloma plasma cell in the bone marrow leads to symptoms that range from anaemia, back pain, and fatigue to kidney and bone damage.

*Multiple myeloma, also known as Kahler’s disease, does not have any effective cure - the disease develops resistance to almost all therapeutic approaches. [SHUTTERSTOCK/Vodolazsky]*
Inequalities in access to myeloma treatment are also an important issue for most of the European countries impacting mainly Central and Eastern Europe – and some non-EU Balkan countries in particular.

“But countries from Northern and Western Europe are also experiencing issues to get access to innovative treatments such as CAR-T therapies in myeloma and other treatments in the heavily pre-treated setting,” said MPE’s Morgan

The representative of the myeloma patients’ association mentioned that another issue in the heavily pre-treated setting is the absence of Phase III clinical trials with comparative data, resulting in a lot of ‘uncertainty’ for reimbursement bodies on whether they should allocate funding.

“Only 6% of the 3,229 worldwide myeloma trials included patients from Central and Eastern Europe countries over the past 20 years, which is something we need to understand and address,” she concluded.

**The role of innovation**

Research and innovation represent the starting point for a new approach to cancer care in the EU, Health Commissioner Stella Kyriakides pointed out at the launch of the **Knowledge Centre on Cancer**, the first flagship action delivered under the Cancer Plan.

This is particularly true for myeloma, where innovation is a crucial component with an expansion in the number and the range of **new treatments for myeloma** which become available in recent years.

The EU’s medicines agency (EMA) acknowledged that new medicines for treating myeloma are needed, as patients who have already been treated with three major classes of drugs to treat this blood cancer – immunomodulatory agents, proteasome inhibitors, and monoclonal antibodies – no longer respond to these products.

A combination of two or three different treatment effects from different types of drugs is commonly used in managing the disease.

Compared to the mono-therapy approach, combining two or more therapeutic agents potentially reduces drug resistance while also providing therapeutic anti-cancer benefits, such as reducing tumour growth and cancer stem cell populations.

“Despite the significant value combination therapies bring to cancer care, there are several challenges to their access in Europe,” a representative from the EU’s pharmaceutical manufacturer association (EFPIA) told EURACTIV.

The current regulatory case-by-case approach to novel oncology combinations is ‘unsustainable’, the representative said, adding that it denies patients access to important new treatments.

For the pharma industry, the way forward should be found in a collaborative approach that takes into account the views of policymakers, payers, authorities, doctors, patients, and manufacturers to address problems in access to combination therapies.
“Research and innovation represent the starting point for a new approach to cancer care in the EU”

Stella Kyriakides
European Commissioner for Health and Food Safety
Long waiting lists challenge Italy’s progress in myeloma treatment

By Federica Pascale | EURACTIV.it

Despite progress in innovative drugs and treatments related to multiple myeloma in Italy, patients warn that long waiting lists in public health facilities still pose severe obstacles.

Multiple myeloma (MM) is a cancer that affects a particular type of bone marrow cells, the plasma cells, which are derived from B lymphocytes and are responsible for producing antibodies to fight infections.

In Italy, it affects about 5,600 people annually and is the second most common blood cancer (10%) after lymphomas, with an increasing incidence (+126%). But survival rates are also increasing, reaching 52.1% in men and 53.6% in women, thanks to the introduction of new drugs for treatment.

However, access to treatment is not always easy when faced with long waiting lists at public health facilities, forcing people to turn to private facilities to get a diagnosis.

Pina C. (77) from Campania, a former professor diagnosed with multiple myeloma in July 2021, told EURACTIV Italy, “Thanks to the treatment I received, I’m better now”.

Although she lives in Calabria, the patient chose to have the necessary medical examinations in a private medical facility in Campania to investigate the origin of her bone pain.

She, therefore, avoided the long waiting lists in public health facilities in Calabria, where there is also a shortage of private health facilities.

Once she was diagnosed with multiple myeloma, she could begin treatment at the Mater Domini Polyclinic in Germaneto, Calabria, near where she lives.

“The bone fractures caused by the myeloma have made all movements difficult, both at home and in the hospital”, she said.

Following chemotherapy, she is now undergoing consolidation therapy to strengthen her bones.

“I am going through a remission phase of the disease, thanks to the expertise of the doctors and the care I received”, she noted.

The role of the Recovery Fund

According to AIOM (the Italian Association of Medical Oncology), in 2020, multiple myeloma cases in Italy accounted for 1.5% (1,759 cases) of all cancers diagnosed in both women and men, with a fairly homogeneous incidence rate both in terms of regional distribution and trends over time.

The incidence of this type of cancer was stable overall, while mortality slightly decreased.

“The therapeutic scenario for multiple myeloma has been progressively enriched with innovative drugs and new therapeutic strategies”, Professor Pierfrancesco Tassone told EURACTIV.

Tassone coordinates a research group to develop innovative therapeutic strategies for treating human malignancies with a special interest in multiple myeloma at Catanzaro University.

“Thanks to the enormous progress in pre-clinical and clinical research, the treatment of multiple myeloma has significantly prolonged, over the past 10 years, the survival of affected patients and improved their quality of life”, Tassone added.

He also emphasised the “invaluable” support received from the AIRC Foundation for Cancer Research and its volunteers, without which the research project, involving several young researchers, “would not even have been possible” in Italy.

“The goal of definitive cure, at present, has not yet been achieved, but the rapid progress of the last few years makes it possible to foresee decisive results in the
“In Italy, thanks to a universalistic system, of which we should be proud, it is possible to access innovative treatments without distinction throughout the country”, the professor says.

However, “the complex and costly logistics of high-tech treatments, which often involve foreign laboratories, could put in crisis even a virtuous system for accessibility to treatments like the Italian one”.

According to Tassone, this is precisely one of the challenges to be overcome through the National Recovery and Resilience Plan (NRPR).
Access to innovative myeloma drugs remains ‘difficult’ in France

By Clara Bauer-Babef | EURACTIV.fr

Over the past ten years, treatments for multiple myeloma have progressed significantly, allowing French patients to live longer. However, much progress remains to be made, particularly in access to innovative drugs.

Multiple myeloma is a rare incurable disease that affects the bone marrow. In France, approximately 30,000 people are affected.

“Today, treatments are very effective and allow for very long recovery periods. Life expectancy has almost doubled in the last ten years,” Laurent Gillot, president of the French Association of Multiple Myeloma Patients (AF3M), told EURACTIV France.

The arrival in the 2010s of new treatments and immunotherapy, which consists of administering substances that stimulate the immune defences of patients, has considerably improved the life expectancy of patients.

“It’s a systematic treatment for everyone diagnosed since 2021,” Gillot said. “This allows patients who had only a few weeks to live to have new remissions of several years,” he added.

According to the latest data, in France in 2018, 5,442 new cases of multiple myeloma were identified, which represented 2% of cancers, according to the National Cancer Institute (INCa). 52% of patients were men.

Receiving a diagnosis is not easy and the disease can be a source of psychological suffering provoking anxiety about the future, loss of reference points, alteration of body image, and difficulty in communicating with loved ones, according to the French Myeloma Intergroup (IFM).

Every year in October, the AF3M organises National Myeloma Day, which allows patients to meet and discuss the disease. The rest of the year, the patients’ and caregivers’ association creates links and provides psychological support and information in every region in France.

“At the regional level, we organise discussion groups. There is an expectation that exists, both on the patient side and the caregiver side. But on the medical level, we are not referrers, we refer to doctors and specialists,” David Bruge, a representative of the Brittany region of AF3M, told EURACTIV France.

Patients also often need logistical help, especially to better understand their rights, such as the use of social workers or hospital relays.
Eric Touroul-Chevalerie is a member of the AF3M association. Touroul-Chevalerie has myeloma himself, while also working as a volunteer, providing other patients with psychological support or information.

“It is essential to help them as a complement to their treatment. Some patients don’t even dare talk about the disease to their loved ones.”

**Progress still to be made**

Hospitals are also increasingly committed to supporting patients beyond the simple medical diagnosis.

They offer psychological support, with the possibility for the patient to request a psychologist, nutritional support, or support from a nurse who can be contacted for various questions.

“The daily life of patients is very disparate and heterogeneous. Each patient is a special case depending on the diagnosis and the state of progress of the disease,” said Bruge.

Although more than half of the patients are 70 years old or older, some people are affected by the disease before the age of 40. They represent 2 to 3% of patients.

However, thanks to new treatments, many patients can return to work. The latest data showed that in the Loire-Atlantique region, two-thirds of the patients were able to rejoin the labour force.

But despite therapeutic advances, there is still progress to be made.

“In myeloma, there are always relapses. So now the challenge is to find treatments that completely cure the disease,” Gillot said.

“We also need to continue to have access to innovative drugs even if they are expensive,” he added. For the moment access is difficult, as it depends on a “problem of evaluation” of drugs at the level of the High Authority for Health (HAS).

Improving the quality of life of patients is also very important, and more attention is being paid to this, especially when it comes to the management of adverse effects of the disease.

Also, while psychological support is essential, less restrictive therapeutic treatments improve daily lives of the patients.

For example, daratumumab, an anti-cancer monoclonal antibody medication, used to require four hours in a hospital and was injected intravenously via a bag. Today, it is injected subcutaneously and takes 30 minutes in the hospital.

In another example, more targeted protocols now exist, notably with messenger RNA and drugs that avoid auto-transplantation and long-term treatment with drugs that avoid chemotherapy.

“This is almost similar to a chronic disease”, said Bruge.

“There is still work to be done, but we see that this is something that doctors and laboratories are taking more notice of,” Gillot concluded.
Innovative therapies bring hope for German myeloma patients

By Julia Dahm | EURACTIV.de

Almost 7,000 Germans come down with multiple myeloma, an aggressive form of bone-marrow cancer, every year, but while mortality rates remain high, research is progressing, giving hope to patients.

While the cancer can often go undetected without major symptoms for a significant amount of time, once symptoms break out, they can significantly disrupt patients’ life.

According to the Berlin Institute of Health, multiple myeloma can cause a weakened immune system, kidney failure, and significant bone loss that can lead to fractures.

“I despared more and more because I was in permanent pain,” one German patient, who reported severe back pain as the symptom that led to the diagnosis, recalled on a cancer patients’ podcast. “Every day, it grew worse,” she added.

In many cases, the cancer is seen as incurable and mortality rates remain high.

Only 54% of women and 56% of men with multiple myeloma survive after five years. After ten years, the survival rate is down to 37% for women and 39% for men, according to the Robert Koch Centre, Germany’s federal health agency.

This is because, even if the cancer is held at bay for several years through therapies, it can become resistant to the medication and eventually grow again.

Still, much progress has been made over recent years and decades, especially regarding patients’ life expectancy.

Twenty years ago, “many patients died of the disease within two or three years,” Udo Holtick from Cologne University explained in a recent publication. Nowadays, he added, it is not unusual for those affected to live for another ten years.

Promising approaches

More improvements could be around the corner as several recent studies show signs of hope for patients. “This is why, over the next years, we can expect a further substantial improvement in the prognosis of myeloma patients,” Holtick added.

One such example is a recent therapy approach called CAR T cell therapy.

Traditionally, multiple myeloma is usually treated through a combination of chemotherapy and stem cell transplants.

CAR T therapy uses genetically modified immune cells to treat cancer in a different way. The gene manipulation enables immune cells to better detect and destroy malignant cells in patients’ blood, bone marrow, and lymph nodes.

“In many respects, this is a milestone,” Max Topp, head of the CAR T cell programme at the University Hospital of Würzburg in southern Germany, stressed.

In early March, the clinic treated the 100th patient with CAR T after administering the therapy since 2016.

Progress has also been made regarding the combination of different treatments – an approach that is seen as especially promising to prevent cancer from becoming resistant to medication.

A recent clinical study conducted by a team of researchers from the German University of Heidelberg and published in Lancet Haematology found that the standard three-way medication mix used as a first treatment for the cancer can see a significantly higher rate of success if it is combined with a so-called monoclonal antibody.
“These are extremely encouraging results,” Hartmut Goldschmidt, who supervised the study, said.

Using the treatment, “we can significantly improve the starting conditions and thus also the chances of success for the following stem cell therapy in a considerable proportion of our patients,” he explained.

**Funding is key**

A key factor for whether research will continue to drive similar progress on myeloma treatments in the future is funding.

Due to its relatively low incidence rate, multiple myeloma is seen as a rare disease. This can bring barriers to funding unequal since incentives to invest in researching treatments are lower.

To tackle this problem, the German research ministry financially supports national research projects and cooperation with other researchers abroad. Under the programme “Research for rare,” a total of €21.5 million is earmarked for research into rare disease treatments.

Meanwhile, once it is developed, medication for rare diseases is also often costly due to the lower number of doses produced.

Contacted by EURACTIV, the German health insurers’ umbrella association (GKV) did not want to comment on whether the financial support myeloma patients currently received is sufficient. Instead, a spokesperson pointed to the responsibility of lawmakers.

“The granting of benefits is based on medical need,” she said. According to the German Social Code, “services must be sufficient, appropriate and economical, and they must not exceed what is necessary,” she added.
Multiple myeloma patients in Spain face regional disparities

By Fernando Heller | euroefe.es

Overcoming the treatment access gap for multiple myeloma, which significantly varies across Spain’s autonomous regions, while also promoting research for new drugs, are priorities, according to Teresa Regueiro, president of the Spanish Community of Patients with Multiple Myeloma (CEMMP).

In an interview with EuroEFE, Regueiro recalls that multiple myeloma, an incurable form of plasma cell cancer, can have continuous relapses.

“The challenge is to overcome these relapses with appropriate treatments for each patient,” she said.

In Spain, there are about 13,000 multiple myeloma patients, all of whom receive support from CEMMP, mainly to inform and provide them with personalised assistance.

To better cope with the physical and mental challenges of living with this disease, among other issues, the “lack of equity in treatments across the national territory” must be overcome, Regueiro said.

“Even within the same autonomous region, hospitals in each province can also choose (which drugs to use), resulting in a complete lack of equity in treatments. Salamanca is a global benchmark, but Valladolid, which is nearby, does not have the same level,” she said.

Regueiro, diagnosed with multiple myeloma nearly 14 years ago, stressed that despite enormous progress in developing drugs, public funding and regional disparities remain an issue.

“When an agreement is reached [with the Ministry of Health] for funding reimbursement, we find, as with many other diseases, that it is not approved in all autonomous regions. On the other hand, each autonomous region can choose whether or not to purchase a particular drug. There is an alarming disparity of situations,” she warned.

Since 2015, several new treatment lines have been approved in Spain, substantially improving the quality of life for multiple myeloma patients.

“Hope lies in clinical trials”, she stressed the importance of continuing clinical trials with new drugs, as multiple myeloma patients can become resistant to some medications.

“We should be very grateful to have clinical trials in Spain. Many patients would die if they didn’t exist. In addition to promoting the advancement of research and treatments, they also favour providing more alternatives for sick people who have exhausted all existing treatment lines,” she noted.

Commenting on the idea that patients should seek treatment in more advanced autonomous regions is unrealistic, she replied:

“You cannot be treated in another region; besides, you would have to register and complete a series of impossible procedures. I don’t see it as feasible, and it wouldn’t be fair to patients either”.

Yet, the president of CEMMP stressed the importance of continuing clinical trials with new drugs, as multiple myeloma patients can become resistant to some medications.

“Extending life expectancy for multiple myeloma patients brings optimism that this pathology may become “chronic”, a concept that Regueiro does not consider appropriate.

“Personally, I don’t like talking about chronicity because, for a patient, chronicity is understood as something for life.’ In our case, you cannot predict how long you will live or how a specific treatment will work,” she notes.
The disease “may be becoming chronic, yes, but understanding that as something that will return or may return. You may have to undergo aggressive treatment again,” she warns.

As for treatments, she said there had been a significant change thanks to new drugs with manageable side effects.

“We have gone from having pure and hard chemotherapy, like the ‘old’ style, to having new agents, including monoclonal antibodies,” she said, adding that until now, the side effects (of the new drugs) have been relatively manageable.

“On the other hand, we are entering the era of immunotherapy, with possible different side effects that will need to be assessed. Until recently, we have been combining a series of new drugs, and the result has not been bad. Many patients are doing well with these innovative medications,” she added.

**The emotional burden**

Referring to a patient’s everyday life, she said if there is no pain or other comorbidity, a ‘normal day’ is like anyone else’s.

“If you regain your quality of life, you will be just as well as others. You will always have something, but, generally, your ‘day-to-day’ will be like any other person,” she said.

In this regard, Regueiro points out that many patients can even consider returning to work.

“You can regain your quality of life, and I would even dare to say that many can regain their work life. There is a certain percentage of patients, especially the younger ones, can return to their jobs,” she said.

However, multiple myeloma patients must overcome various barriers and practice daily resilience, as with any disease.

“Although the goal is for patients to have the best quality of life, there is a strong emotional burden in myeloma,” she says.

“When you have cancer, they don’t tell you from day one: ‘You have incurable cancer and will have relapses.’ They tell you the opposite. The emotional burden of knowing that you are ‘fine’ but can relapse at any moment cannot be avoided. It is something very strong to bear mentally,” she concluded.
Multiple myeloma therapies in Poland are becoming increasingly effective

By Bartosz Sieniawski | EURACTIV.pl

Treatment of multiple myeloma has come a long way in Poland as the state has added more therapies in its reimbursable drug programme, stakeholders have said but stressed the need for more efforts on potential bone marrow donors who provide another vital treatment option.

“Treatment has improved significantly in recent times. Recently, substances that were not available for a long time, have been included in the reimbursable drug programme. This makes myeloma treatment more effective and free of charge in Poland,” UMED Professor Paweł Robak told EURACTIV.pl.

Multiple myeloma is a malignant cancer that attacks the human blood. Until recently it was considered fatal but is now said to be chronic – which means that it does not necessarily end in a quick death of the patient.

“Myeloma is a rare ailment, but among haematological malignancies, it ranks second. For oncologists, its treatment is a daily occurrence. Therapy involves the combination of several types of drugs, depending on the patient's health and general condition,” the doctor explained.

The disease is difficult to diagnose and blood cells multiply uncontrollably.

There are currently approximately 10,000 myeloma patients in Poland while between 2,000 and 3,000 new cases are diagnosed each year.

With treatment, myeloma patients can survive from five to six years and sometimes even more than a decade. Unfortunately, myeloma is an incurable and relapsing disease: As many as 30% of patients diagnosed with this cancer in Poland die within 2.5 years from the start of treatment.

According to stakeholders, Poland is not lagging behind others in Europe as it reimburses drugs for patients suffering from myeloma, essentially making the treatment of the disease free.

“When it comes to the availability of myeloma treatment, we have nothing to be ashamed of in Poland,” Robak said.

Multiple myeloma therapy can be carried out in a number of ways.

One of the most important treatments a person with the disease can receive is a bone marrow transplant. Most often, myeloma patients are transfused with their own haematopoietic progenitor cells, which have previously undergone appropriate treatment outside the patient’s body.

In addition to this method, which can only be used for patients who meet the appropriate requirements (low enough age, no contraindications to transplantation), chemotherapy is also used to treat myeloma.

The drugs used to treat myeloma are a group of about 15 substances that have been registered in the last 20 years.

Poland updated the list of state-funded myeloma treatments in January 2023, which doctors describe as an “exceptionally big step forward” in the treatment of malignant tumours.

Bone marrow transplants

A bone marrow transplant is one of the more effective treatments for multiple myeloma. However, not every patient is suitable for this procedure – for example, transplantation is not performed on elderly patients, who make up the vast majority of myeloma patients.

A bone marrow transplant, if possible, is preceded by intensive chemotherapy and radiotherapy for the patient in order to reduce the number of cancer cells in their body as effectively as possible.

Another problem with bone marrow transplants is that it is difficult to find a ‘genetic twin’ from whom the tissue can be taken. Most often, family members become bone marrow donors, but in cases where this is not possible, it is necessary to look among registered
donors for volunteers.

In Poland, more than two million people are registered in a database of potential bone marrow donors. As people dealing with oncology patients point out – this is still not enough.

“Patients first have to face the diagnosis and then the uncertainty that comes with the knowledge that their life fully depends on someone else. This is another stage of anxiety during the illness. You don’t know if there will be someone to help,” Dorota Raczkiewicz, president of the cancer patients foundation Drużyna Szpiku, told EURACTIV.pl.

“It is very important for the patient to have the feeling that this other person will be found and will not withdraw the decision to become a donor,” she added.

Raczkiewicz stressed that there are currently more than two million people in the Polish register of potential bone marrow donors while 15 years ago it was only just over 30,000 people.

“You can see the colossal work of activists, doctors and the media who have managed to convince the public that with a harmless procedure – a bone marrow transplant – someone’s life can be saved”, she noted.

After Germany, Poland has the second largest base of potential bone marrow donors in Europe. Across the continent, ten million people are registered.

“However, this is still not enough, as finding a genetic twin for a particular patient is difficult – and anyone in any country can develop cancer,” Raczkiewicz said.

In 2022, the A. Mielęcki Independent Public Clinical Hospital in Katowice – the leading bone marrow transplant centre in Poland – performed a record number (326) of blood-forming tissue transplants for the country, 57 of which required a separate donor.

In 2021, 310 such procedures were performed, and 312 in 2020.

Image below: Microscopic image of bone marrow multiple myeloma. [Shutterstock/ Babul Hosen]
There are currently approximately 10,000 myeloma patients in Poland while between 2,000 and 3,000 new cases are diagnosed each year. [Shutterstock/ Nemes Laszlo]