Myeloma Symptom Translator

Medical professionals and patients can use very different language to describe the same symptoms. The often vague symptoms of myeloma can be difficult to explain to others. This translator is designed to help communication between a doctor and patient by sharing examples of myeloma symptoms described in patients' own words.

Myeloma is a blood cancer that can be hard to spot, yet it can be diagnosed using a simple blood test. If your patient presents with these symptoms we are asking you to consider that it could be myeloma.

Symptoms

Symptom	Medical description	#InMyeOwnWords (Taken from real patients)
Pain	The pain is frequently a persistent dull ache, which may be made worse by movement.	"Bones were aching, felt as if my bones were being squeezed in a device."
		"It was like a small elastic band was pulling my shoulder blades together. When I tried to lift my arms to brush my hair, the elastic band got even shorter and tighter."
		"I thought I had pulled a muscle in my back. I had a pain in my back that gradually got worse. As I thought it was muscle damage I went for physiotherapy."
Easily broken bones/ myeloma bone disease	The middle or lower back, rib cage and hips are the areas most likely to be affected, causing pain in these areas. Myeloma bone disease can also cause bones to fracture more easily.	"Lying flat in bed became impossible, I used to sleep sat up in a chair. When I lay flat I felt like I couldn't breathe."
		"I felt a *ping* in my lower spine. It just happened, no rhyme or reason, just *ping* and boy after that was the pain bad!!! Couldn't stand without pain, couldn't sit or lay down! Going from being (*almost*) fine to suddenly immobile is awful!"
		"My fall from a low stool initially felt like I might have caught a nerve, due to the sharpness of pain. I didn't imagine a fall from less than a couple of feet would cause my bones to break."

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Recurring infection	Frequent or recurrent infections including: • Bacterial infections • Viral infections • Fungal infections There could also be an absence of any underlying conditions.	"Stumbling from one infection to another with no break." "Lots of chest infections and picked up any illnesses going." "Had urine infection it would go away for a while but always came back."
Fatigue	A feeling of extreme tiredness, lethargy or exhaustion, which persists most or all of the time.	"It was like I was a toy that had run out of battery." "Yes, I was able to do 10,000 steps a day but this fell to 2,000 or less." "I could fall asleep anywhere very quickly even if I had slept all night. I could be falling asleep after breakfast!"
Kidney damage	Experiencing any of the following symptoms: • Thirst • Fatigue • Persistent headaches • Loss of appetite • Nausea and/or vomiting • Passing excessive amounts of urine, or very little or no urine • Swelling in the face and ankles • Shortness of breath	"I was urinating so much and it was clear and frothy, no colour to it all. I later found out my kidneys were failing." "Waking at least twice in the night needing to urinate." "Urine smelled different and more strongly."
Peripheral neuropathy	A feeling of 'pins and needles', numbness, unusual sensations and/or increased sensitivity to touch in the hands and feet.	"My feet felt like ice to me but when I touched them they were actually hot." "Tingling in fingers and toes, at night I felt like I had been plugged into the mains!" "Not numbness more heavy, burning feeling in calf muscles."

If you suspect myeloma based on any of the above symptoms and/or your clinical findings, consider arranging the following tests:

- Serum protein electrophoresis for paraprotein
- Serum free light chain (sFLC) assay
  - If unavailable, urine Bence Jones protein (BJP)
- Serum immunoglobulins (IgG, IgA and IgM)
- Full blood count
- Corrected serum calcium
- Serum creatinine

We know the pressures that GPs face which is why we've developed educational tools for healthcare professionals. Scan the QR code or visit the link to access our free resources **myeloma.org.uk/gp**

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