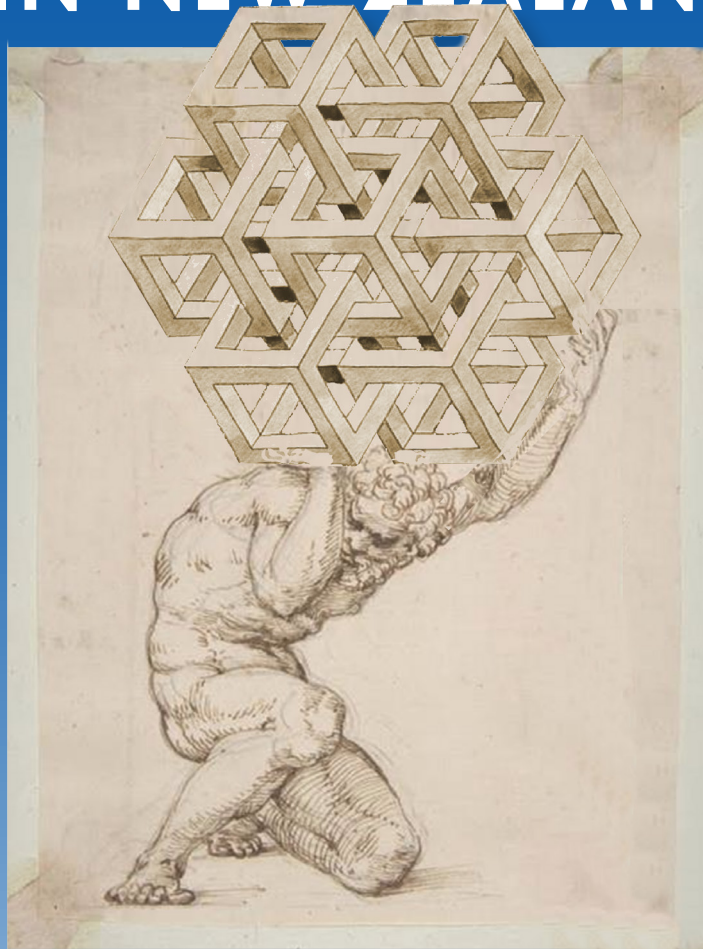


MANAGING **MULTIPLE MYELOMA** IN NEW ZEALAND



PATIENTS' PERSPECTIVES

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Published by Myeloma New Zealand
Registered Charity No. CC53924
PO Box 25162
Wellington 6011
New Zealand

www.multiplemyeloma.org.nz

ISBN: 978-0-473-48524-5 - print
ISBN: 978-0-473-48525-2 - online/PDF

Cover design by Dennis Hearfield
Printed by City Print Communications

MANAGING MULTIPLE MYELOMA IN NEW ZEALAND: PATIENTS' PERSPECTIVES

A survey of patients and carers on the personal, psycho-social and financial costs of myeloma in New Zealand, undertaken by Myeloma New Zealand, September 2018

Survey design and analysis prepared by Maddie Shannon and Joanna Bullock

"Sorrow. Feeling 'different' from other people. Isolation. Uncertainty."

"Confusion, inability to communicate, muscle wastage, tiredness, constant sleeping, frustration, fear of the unknown, lack of understanding of what to expect."

"Myeloma has a major impact on my independence, my ability to earn a wage to live, the ability to complete simple tasks such as vacuuming, due to the pain I have."

"Horrific. Ended up in critical care and life support. Very nearly died. Traumatized for months. An absolute nightmare."

"We are just so tired. This disease and this process just wears you down and you feel you don't have a voice."

"I am still an eternal optimist. If anything the diagnosis has given me a greater appreciation for each day I am blessed with."



Myeloma New Zealand is a charitable trust established in 2016 to focus specifically on multiple myeloma and to improve the quality of life and survival of New Zealanders living with it.

We are primarily a patient advocacy organisation, that seeks to empower patients with information, research and support; to advocate with government to allow myeloma patients access to the remarkable treatments that are transforming lives and survival in other comparable countries; and to raise awareness and understanding among the general public of myeloma, one of our most common blood cancers.

FOREWORD



Ken Romeril
Chief Executive
Myeloma New Zealand

Understanding the personal burden of multiple myeloma for those New Zealanders and their families who are living with it is a crucial part of our endeavour to chart the way forward for the treatment of this cancer in our country.

We are very grateful to those who took part in this, our first survey of patients and their carers, and those who contributed their stories and experiences to our wider study. Clinicians, haematology nurses and others of us who are working in this field know only too well the life-changing challenges, pain and distress faced by patients diagnosed with myeloma. We need to build greater understanding of this cancer among the wider public and, in particular, among the public policy makers who guide and make the decisions about how myeloma can be treated in this country.

The survey has given us clear messages about patients' priority needs: more and better information about myeloma and its treatments; stronger advocacy for new treatments and clinical trials; and better support and preparation for the emotional and psychological impacts of living with myeloma.

Our message in this study is one of hope: confidence in our constantly improving understanding of this complex disease and its multiple presentations, and how we can use this knowledge to tailor treatment to the individual patient; and confidence in the array of revolutionary new treatments that are continuously coming on stream. There are strong grounds for hope that over time we will see this disease become a chronic condition rather than a fatal one, with much improved quality of life for those who have it.

Gaining a more detailed understanding of the experiences and needs of patients, together with the important data gathered in our burden of disease report, is a significant step forward towards this goal.

A stylized handwritten signature in blue ink, appearing to read 'K. R. Romeril', with a long, sweeping underline.

Ken Romeril MBChB, FRACP, FRCPA
Chief Executive
Myeloma New Zealand
NZ Member of the International Myeloma Working Group

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RESEARCH METHODOLOGY

- The data presented was collected in August and September 2018.
- A total of n=128 people completed the survey.
- Respondents clicked on an anonymous survey link on the Myeloma New Zealand website. This significantly increases self-selection bias, and means the group that chose to respond to this survey may not be fully representative of the views of the overall New Zealand myeloma patient and carer population. It should also be noted that members of support and advocacy groups are sometimes those most in need of support and may also be those who are more forthright in their views. Other points to note in respect of the group of respondents are included throughout the analysis.
- The data has not been weighted.
- The questions asked, and the sample sizes for the number of people who answered each question, are included in this analysis (n=XX).
- Where averages were calculated from a scale, mid-points of ranges are used (e.g. 10 – 20, midpoint of 15) to create a rudimentary average.

SURVEY DEMOGRAPHICS

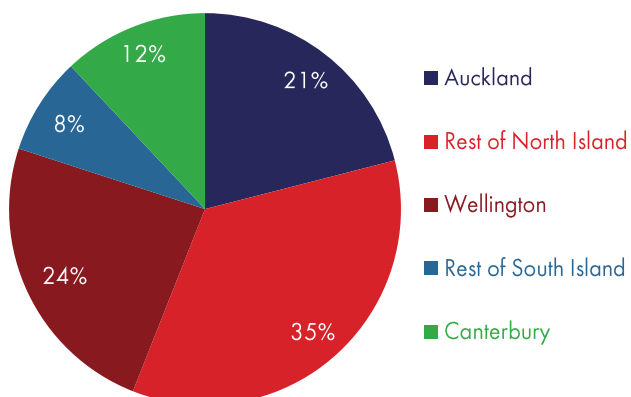
Respondents:

- 128 respondents (of a NZ patient total of 2,500)
- 64% patients, 35% carers on behalf of patients
- 80% from the North Island
- 89% European, 7% Māori

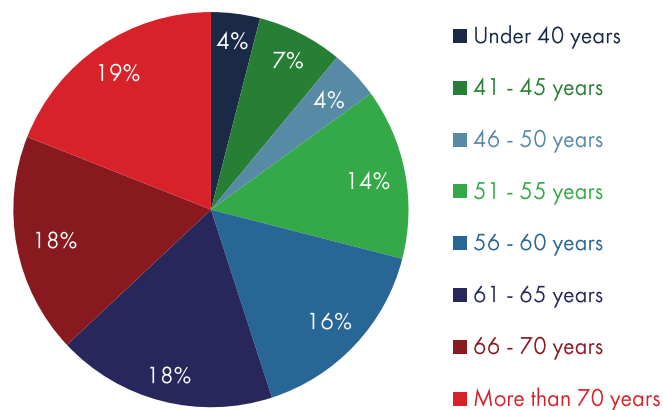
Patients:

- 55% aged 61 – 70+, 30% aged 51 – 60, 15% under 50*
- 33% have had myeloma for more than 5 years, and another third for between 2 and 5 years.
- 42% were diagnosed by a haematologist and 38% by a GP.

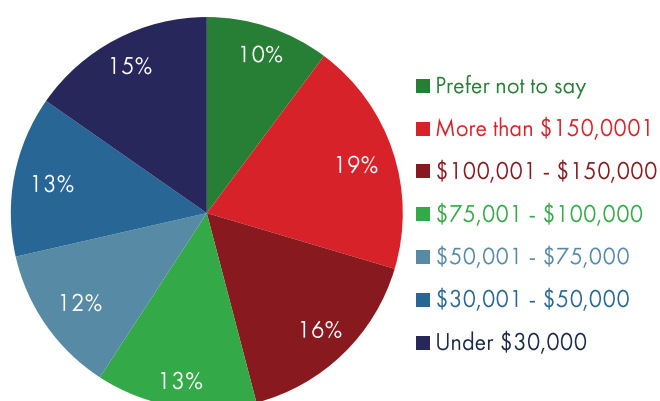
Region



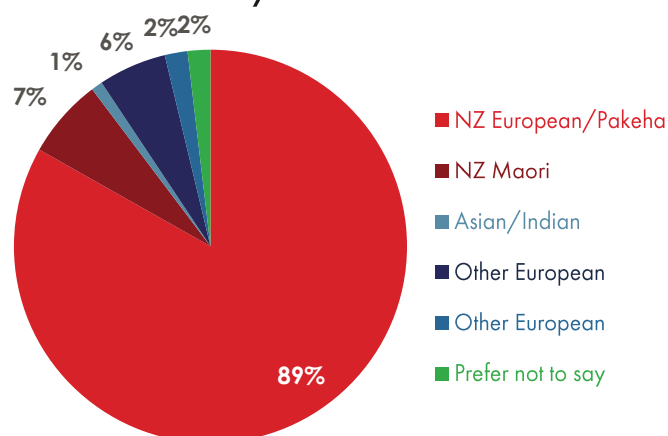
Age group of patients



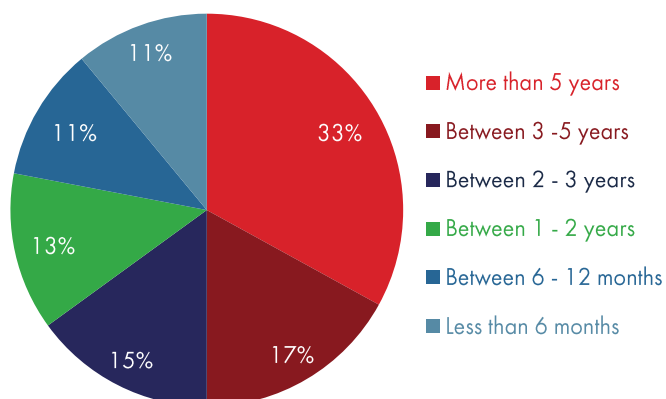
Household income



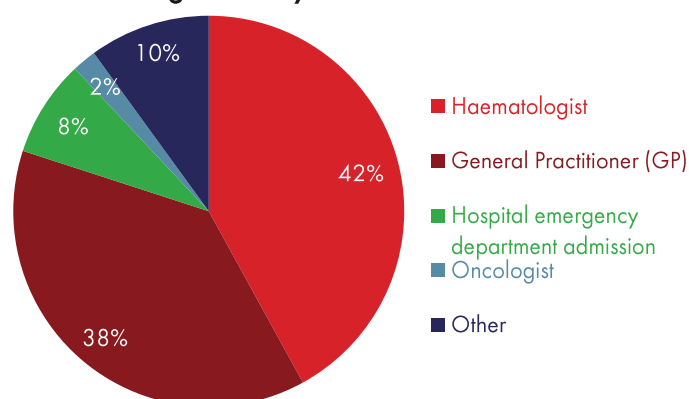
Ethnicity



Length of time since diagnosis



Diagnosed by?



*Only 19% of patients covered in the survey were over 70 years, while 50% of patients New Zealand-wide are over 70. This will bias the 'loss of income' findings.

EXECUTIVE SUMMARY

Living with myeloma

Day-to-day impact

Myeloma has an immense impact on patients and their carers, both in everyday life and on their overall future. They have to come to terms with a shorter life expectancy and the reality of no known cure.

Most patients experience fatigue on a daily basis, many are anxious and/or in pain every day, and many suffer from depression due to their illness. Myeloma affects their ability to participate in sports or recreational activities and their earning potential, and for many the disease has impacted heavily on their intimate relationships.

Many describe heightened stress levels, falling self-esteem and confidence, feeling out of control and a loss of personal identity. For a few, however, myeloma has changed their perspective on life and taken them away from the 'treadmill of work'.

The most difficult and challenging aspects of living with myeloma are:

- fear and uncertainty
- mental health issues, including sometimes terrifying mood swings and personality changes
- loss of 'self'
- loss of physical abilities, independence and income
- coping with harsh medical treatments and procedures, and severe and debilitating side effects, and
- lack of preparation and emotional support for the 'journey'.

Time taken to diagnose

Most myeloma patients were diagnosed relatively quickly, many within three months. In some cases GPs were quick to recognise unusual symptoms and quick to refer them for treatment. Some patients acknowledged that myeloma is not well understood and is difficult to diagnose.

However many felt their GP did not do blood tests early enough. They described episodes of GPs misunderstanding their symptoms, some being treated for flu or anaemia, with pain relief for back pain, and antibiotics for recurring infections, before eventually being diagnosed with myeloma. A few noted their diagnosis was incidental to a cholesterol investigation and some felt their doctors should have known that shingles might be a trigger factor.

At the other end of the spectrum a sizeable number of respondents had suffered years of misdiagnoses and potentially preventable, debilitating pain, and felt the disease is not well enough understood, especially by GPs, but also by specialists. Quite a few had to move to another GP or make multiple trips to ED to get the correct diagnosis.

Treatments

Almost 8 in 10 patients have had induction chemotherapy, and two-thirds have received an autologous stem cell transplant (ASCT).

Going through the ASCT was in many cases a harrowing experience for both patients and carers, although views were often coloured by whether or not the transplant was successful and the length of remission it provided. Severe nausea, fatigue, lethargy and diarrhoea, isolation due to the risk of infection, continuing compromised immunity and the very long road to recovery were among the worst aspects of the treatment.

While some patients were unhappy with hospital staff and ward arrangements, many acknowledged the care and support of medical staff and their own family members. Being well prepared and fully informed was also an important factor in getting through the ordeal.

Despite side effects and the many challenges of undergoing ASCT, a number of patients have an overall positive view of the experience.

Financial impact

Employment status

Over a quarter have had to leave full-time work, many having to stop working or retire early. The majority of those who were employed discussed their diagnosis with their employers, who were generally very supportive. Many provided ample sick leave and reduced or flexible work hours.

However a few employers proved to be unsympathetic or inflexible. Patients and carers who had their own businesses or were self employed were hard hit.

Absences from work

Almost a quarter of patients/carers have missed over 200 days of work since their diagnosis, significantly affecting income and increasing stress levels. One in five were already retired or retired early.

Costs

Insurance premiums and the costs of private specialists are the major contributors to the increase in patients' costs due to myeloma diagnosis. Alternative treatments, medications, and travel and accommodation are also significant costs.

The average amount a patient or caregiver has spent annually in relation to myeloma is approximately \$7,600 and the estimated average loss in income of a myeloma patient since their diagnosis is over \$100,000.

Satisfaction with care in New Zealand

Most patients/carers feel satisfied with the overall level of care, although around a fifth are not satisfied. There is lower satisfaction with the quality of treatment available in New Zealand, with almost a third feeling it is average or of low quality.

Half of myeloma patients/carers are happy with the information available on myeloma in New Zealand, but those who are not want more information on research, treatments and clinical trials.

Medical professionals are doing well in explaining treatments and procedures, but some patients felt they were rushed into treatment after diagnosis, before having time to fully understand what was going to happen and the likely side effects.

Patients and caregivers highly rate the level of support they receive from their family, their specialist and their haematology nurse.

Over half of patients or caregivers have at least some level of doubt about their understanding of their condition.

Many patients have tried alternative or complementary therapies, the most common being dietary supplements or physical/exercise therapy.

Some found them helpful in managing symptoms, mental health, energy levels or reducing pain. Many felt just 'doing something' helps, but others were unsure of any benefit. Some patients still just felt very lost, tired and in need of more support and advice.

How can Myeloma New Zealand help?

Patients and carers want information about latest treatments and clinical trials, advocacy for new treatments, seminars with experts, support and connections with others going through the same journey, and training and support for carers and families.

The majority of comments concerned the need to advocate with government for funding new treatments.

There is also a strong desire for simpler, more comprehensible information about tests and treatment pathways, more advice about what to expect as the disease progresses, and a guide to all the support services that are available. A 'Here's what you need to know' pack would be very valuable.

More seminars around the country including the regions from experts on an array of subjects would be welcome. Topics should include latest international research, advances in treatment, the various phases of myeloma, pain levels and management, and mental health issues. They would also like to see training for carers, question and answer sessions (preferably online), and the opportunity to meet and talk with other myeloma patients and carers.

Of the patients and carers who took part in the survey, 81% said they would be interested in participating in further research.

Advice for the newly diagnosed

Patients offered many tips for the newly diagnosed: don't panic, stay positive, take one day at a time, be very well informed about myeloma and the treatments, connect with others like you, and take advantage of any support, assistance or information you can.

Recommendations

1. Better mental health and emotional support

Patients and carers need better preparation and support throughout the treatment process, particularly when undergoing difficult procedures such as ASCT. This includes access to counselling and mental health support, ways to connect with other patients and support groups, and training for caregivers, particularly in coping with patients' depression and mental health issues.

2. More intelligible, more timely information

They need more, better information, presented in a way that is easy to understand, and at the right time. They want information including seminars and expert talks about: the disease and its many treatments; survival rates; new treatments; clinical trials and research; and compassionate access programmes.

3. Advocacy for new treatments

Patients want Myeloma NZ and other related patient groups to actively advocate to government to fund new treatments and facilitate the opening of more clinical trials and access programmes.

4. Education of medical professionals on myeloma

They also see better education of GPs and medical professionals to improve understanding of myeloma as critical. Upskilling doctors at the frontline should lead to earlier tests and earlier diagnoses.

5. Greater public understanding of myeloma

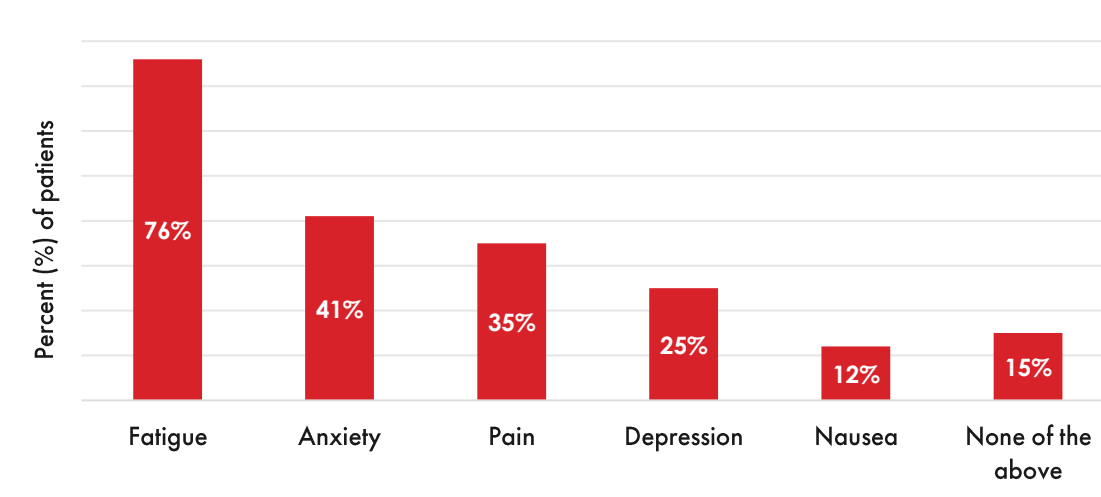
Patients and carers would also like to see information programmes that generate greater public understanding and awareness of myeloma.

I LIVING WITH MYELOMA

Three-quarters (76%) of myeloma patients experience fatigue on a daily basis, 41% are anxious and over one third (35%) are in pain every day. Additionally, one quarter are experiencing some type of depression due to their condition.

Figure 1 - Day-to-day impacts of myeloma

Q -Does myeloma cause you to feel any of the following on a day-to-day basis? (n=105)



The most difficult and challenging aspects of living with myeloma

- Fear and uncertainty
- Mental health issues
- Coping with pain and fatigue
- Loss of physical abilities and 'self'
- Loss of independence and income
- Coping with medical treatments, procedures and side effects
- Lack of preparation and emotional support



In their own words:

"Not knowing what's coming up next..... like 'when is it coming back? What's the next thing to go wrong?'"

"The absolutely terrifying mood swings with Dex[amethazone].... resulted in my spouse being very unpleasant and many family arguments. He felt like he didn't have control over his emotions and this was horrible. There were times we didn't want to interact with him because of how he might react. It was like walking around on egg shells.... We're not equipped to handle this nor trained or counselled."

"Myeloma has a major impact on my independence, my ability to earn a wage to live, the ability to complete simple tasks such as vacuuming due to the pain I have, the reliance I have had to accept from my whanau & friends."

"Fear of a shortened life. No energy, limited physical ability, now going through chemo..."

"Losing my independence and my income."

"Not knowing what the future holds and how long my husband will be alive for, when will the myeloma get worse and how will we cope..."

"Consolidation with chemo post-transplant was long acting and created many treatment-related physical and mental problems."

"Sorrow. Feeling 'different' from other people. Isolation. Uncertainty."

"The shattering decrease in my physical abilities and fitness."

"Letting go of previous retirement plans."

"The whole experience has been difficult. This disease has changed our lives significantly. Whilst the hospital has been efficient in handing out medication, there has been absolutely no emotional or spiritual support. No primary nurse either....Appointments are very rushed, and Mum is sometimes treated in a patronising manner so I always make sure to go with her."

"Stem cell transplant."

"Struggling with tasks I used to do easily, depression episodes from small set-backs and other minor ailments, relationship issues."

"Sudden lack of sex life."

"I feel that I am a burden to my partner/family because of the things I can no longer do."

"Coping with the side effects of treatment."

"The effects of Dex landed him in the psycho ward for two months ...[though he had] no previous history of mental disorders."

"...hoping I won't have to go into care. Loss of earnings and losing my sense of self."

"Being unable to do normal tasks. Remembering things. Trying not to be too sick or tired to participate in family gatherings. Loss of life and living on a knife edge."

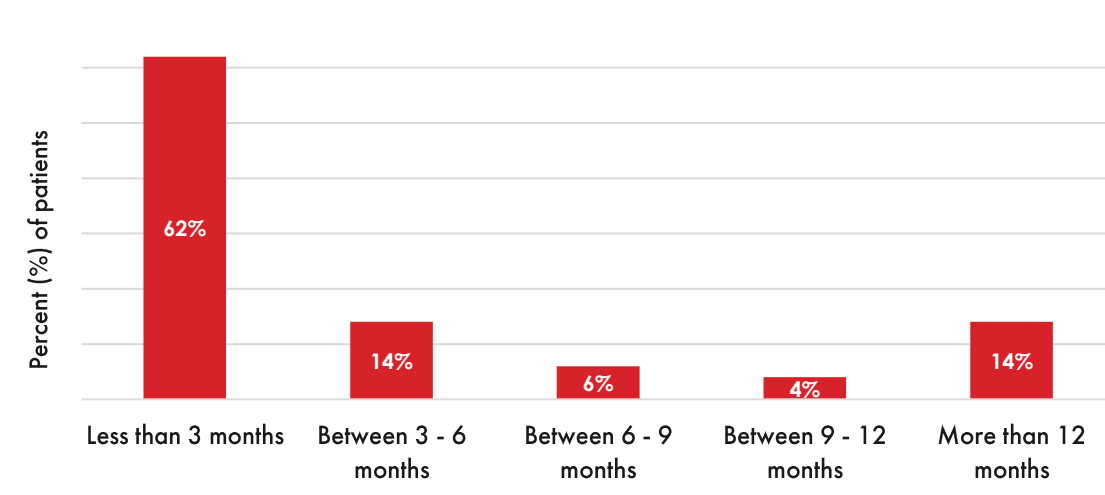
"I guess as a family we look at our lives as before and after this dreadful diagnosis....We still have Mum with us but she is not the same. It's a very confusing disease where the treatment goes on and on and she feels like a guinea pig. She has never been depressed in her life but this condition has made her depressed, and as her main support person it has been so challenging in so many ways. There is no support for families, nothing around the reality of what is in the future and dealing with issues around death. This has never even been addressed. It's just left to the family to guess."

Diagnosis

Most myeloma patients were diagnosed relatively quickly, with 62% diagnosed within 3 months. However for 14% it took more than a year to be diagnosed.

Figure 2 - Time taken to diagnose

Q - Thinking specifically about when you were first diagnosed, how long after initial presentation to a medical practitioner was myeloma diagnosed? (n=128)



Many of the patients who were diagnosed in a reasonably short timeframe said their GPs were quick to recognise abnormal results or unusual symptoms and quick to refer them for treatment.



In their own words:

"My own GP was completely onto it, and referred me to the hospital haematologists within a matter of days of seeing him and getting my blood test results."

"Attended my GP with several random 'symptoms' and told it was probably a virus, and if not better in a couple of days to get blood test. I did that and was then told to get a second test. Saw a GP on the Monday, a haematologist on the Wednesday, and started treatment the following Friday. Could not possibly have asked for more."

"It is not an easy illness to diagnose and my husband did not have the classic symptoms. He was lucky that the haematologist recognised the indicators in the results from his blood tests."

Many respondents acknowledged that myeloma is not well understood, and is difficult to diagnose, especially when a patient does not have the 'classic' myeloma symptoms. Nevertheless many felt their GP did not do blood tests early enough. They described episodes of GPs initially missing or being confused by their symptoms, some being treated for 'flu or anaemia, with pain relief for back pain, and antibiotics for recurring infections, before eventually being diagnosed with myeloma. A few noted their diagnosis was incidental to a cholesterol investigation and some felt that their doctors should have known that shingles might be a trigger factor.



In their own words:

"I was diagnosed in the early stages but only after I'd had worsening anaemia for several months, flu-like symptoms regularly and bone pain. A gastroscopy and colonoscopy confirmed no issues, so obviously it was another problem."

"I was asymptomatic and was diagnosed incidentally during investigation of high cholesterol."

"Was promptly diagnosed but had been unwell on and off for a few years. MM was advanced so possibly could have been picked up earlier by GP."

"I went to the GP 3 x beforehand and was told to go to a chiropractor. Maybe blood testing should have been suggested earlier?"

"Should have been picked up earlier but appears not well known. My GP was clueless and kept treating me with ibuprofen for rib pain. Referred me to an endocrinologist after a blood test showed low iron. Finally had a CT scan after he couldn't find anything obvious. Came back with diagnosis of multiple myeloma.There is not a lot of awareness of MM symptoms by GPs in general. I had months of pain and frustration before getting a correct diagnosis."

"My wife and I both suspect she had MM long before she was given the blood tests that admitted her to hospital, ie she kept getting repeated urinary infections for which the GP gave antibiotics."

At the other end of the spectrum a sizeable number of respondents felt very strongly that medical professionals were taking much too long to find the cause of their symptoms. Many had suffered years of potentially preventable debilitating pain, and felt the disease is not well enough understood, especially by GPs, but also by specialists. Quite a few had to move to another GP or make multiple trips to ED to get the correct diagnosis. A number described years of misdiagnoses.



In their own words:

"My son had debilitating back pain from age 27 until diagnosis of myeloma (Solitary Plasma Cytoma) aged 31 years. There was ongoing misdiagnosis by GPs, a rheumatologist, and an orthopaedic surgeon during this period. Eventually my son started losing feeling and function in his legs, and an after-hours GP contacted the Neurology Department. They admitted him urgently through the Wellington Hospital ED. A large lesion was found in his spine, and he felt overwhelming relief that the pain 'wasn't in his head' and 'able to be controlled by a spa bath and exercises'."

"Crippling spasm attacks. Three collapsed vertebrae. Lost 8 kilos in weight. Husband took me to doctors, hospital in wheelchair, sent home!"

"Many visits to doctor with back pain. Not diagnosed until went to the emergency department."

"In the 6 months prior to diagnosis, in chronic pain, I had been seen by GP, neurologist, neurosurgeon, pain specialist and orthopaedic specialist. I had blood tests and 2 MRIs... and steroid injections in my lumbar spine. Even though the scans showed multiple

fractures in my spine...at no time did anyone mention that it might be MM. The pain was so severe I could barely breathe... and two weeks before I was finally diagnosed I had pain so bad in the top of my right leg I couldn't walk. The ortho specialist admitted me to hospital with a suspected broken hip. After more x-rays and scans they found 2 spots on my pelvic bone, hence I was given a bone marrow biopsy, and then was told I had MM (stage 3). I have been left severely disabled and feel this could have been prevented if I was diagnosed sooner."

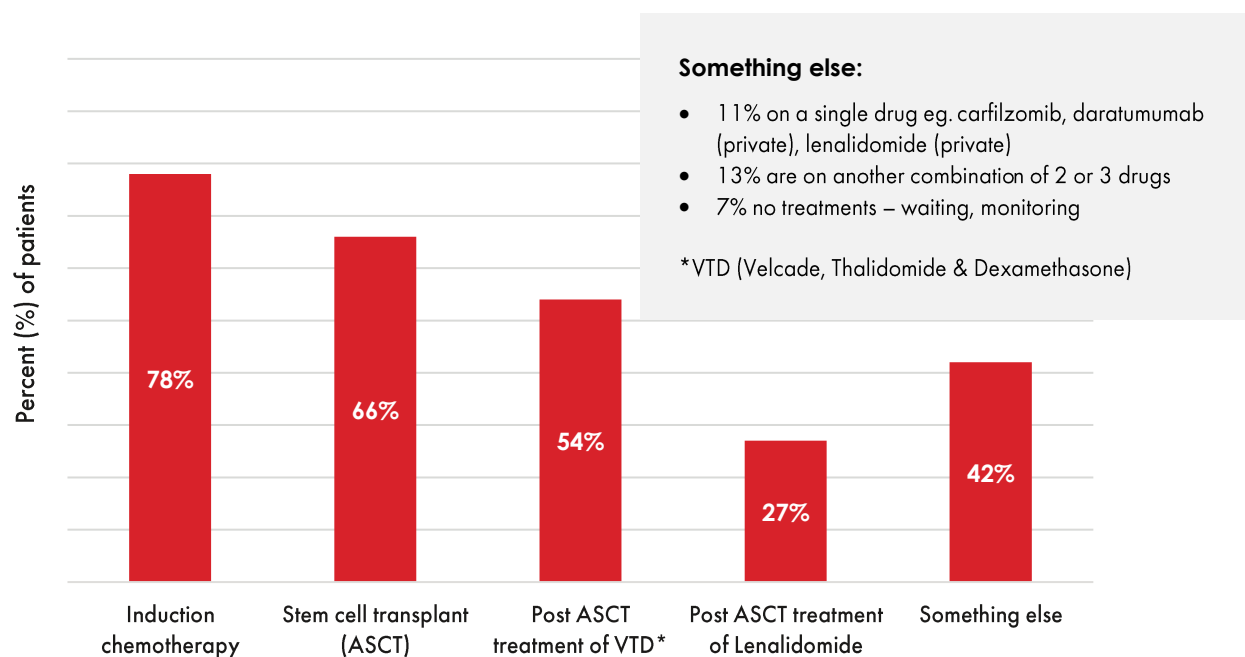
"A surgeon removed my gall bladder to alleviate pain to no avail in spite of my GP detecting MGUS a few months earlier. Meanwhile a tumour was crushing my spine."

Treatment

Almost 8 in 10 patients have had induction chemotherapy (78%), and two-thirds have received an autologous stem cell transplant (ASCT).

Figure 3 - Treatments undertaken

Q - From the list below, please select the treatment(s) you have undertaken for your myeloma. (n=106)



Stem cell transplant

Going through the stem cell transplant was in many cases a harrowing experience for patients and carers, although views of the experience were often coloured by whether or not the transplant was successful and the length of remission it provided. Severe nausea, fatigue, lethargy and diarrhoea,

isolation due to the risk of infection, continuing compromised immunity and the very long road to recovery were among the worst aspects of the treatment.



In their own words:

"Horrific. Ended up in critical care and life support. Very nearly died. Traumatized for months. An absolute nightmare."

"First ASCT was a horrendous experience, with infections and fall onto toilet causing two spinal compression fractures. Discharged home after 5 weeks, on walking frame and weighing 40kg. A couple of days later admitted back in for a further 2 weeks. ...Not all bad news though – overall result was VGPR [very good partial response]. The second one was easy!"

"On the negative side I was told I was "low priority" because I had myeloma... I was sent home (pic insitu) when a priority took my place ... found my specialist unapproachable and not overly caring. ...I was very ill during ASCT, but survived and there is the positive. I am still here."

"It was the most difficult thing I've ever done. The long period of recovery was the most challenging, as every other time I've been in poor health I've improved from one day to the next. When the improvement is too slow to notice it is very difficult."

"Exhausting at the time but so worth it!"

"It was a hard 6 months, but gave me 5 years before I needed further treatment."

"Recovery was tough and took at least 100 days."

"Awful, got bilateral pneumonia, lethargic, diarrhoea."

*"It knocked the living s*** out of me and I was off work for 6 weeks without having a positive result."*

"It was an extremely gruelling process, got infections afterwards as well, and the myeloma came back within 3 months."

"Very tough physically and on the family. None of the transplants were very successful."

"Most horrendous part of the treatment. Ten days after the ASCT I was hospitalised with infection for 5 days. I only got around 15 months remission from my ASCT. I would most probably have a completely different view of the SCT if I was still in remission as a result of it."

"Without sounding shallow the hair loss and the amount of time it took for it to grow back was personally very hard for me."

While some patients were unhappy with hospital staff and ward arrangements, many acknowledged the care and support of medical staff and their own family members, and how important this was in helping them through this difficult process. Being well prepared and fully informed was also an important factor in getting through the ordeal.



In their own words:

"It's a hard procedure - well supported by the SCT nurse with preparation, the hospital and specialist and family and friends. Unfortunately it was not successful, and relapsed within a year."

"The SCT was a pretty harrowing experience. The nausea I experienced was like nothing I can ever explain but I was thoroughly prepared for it by the transplant team. There was nothing I went through that was a surprise [and] it was not as scary because I knew what I was experiencing was completely typical. This made a huge difference for me. It was an extremely hard thing to go through but I have had a really good outcome thus far."

"A traumatic experience but an incredible team of nurses and specialists and care was exceptional."

"The excellent care I received from the transplant team at Wellington Hospital was faultless and I'm very grateful to them."

"It was a dreadful experience but it was superbly organised and I was well cared for."

"Wonderful support by the staff at Christchurch Hospital."

"The SC harvesting didn't go according to plan, but with correct drugs produced a positive result. At first this was terrifying and very disappointing, but once sorted was elated. The hospital staff and specialist were absolutely fantastic throughout the procedures. They explained things clearly and took us on the journey. The nurses were so compassionate, friendly and helpful. ...I stayed at the hospital most days and until late at night and the staff welcomed me being there to care for and support him. Some of the after effects of treatment were very unpleasant and as a carer I felt so incredibly sorry for my husband as there wasn't much I could do. Thankfully I had an extremely understanding employer and was able to give my husband the care and support he needed until he was well again."

Despite side effects and the many challenges of undergoing ASCT, a number of patients have an overall positive view of the experience.



In their own words:

"I was delighted to be able to have a transplant after successful treatment with Velcade. Although I was pretty sick afterwards (as expected) it kept the myeloma at bay for 7 years. I was back at work after 3 months and felt great."

"I generally handled the transplant very well, the staff at Auckland Hospital were excellent. Process relatively simple and straight forward. Negatives were lack of people contact after for a period which forced me to sell my business. Obviously you are impacted in energy levels and immune system but these did not become major hurdles"

"I'm back walking x 2 a week and playing golf once a week. Still get tired and side effects of some of the maintenance drugs. Have not had a holiday for 18 months due to chemo/harvest/SCT/maintenance treatment. But I feel I'm turning a corner 😊."

"Very positive – quite tiring but I was lucky and had no infections and only 2 nights in hospital."

"Experience was positive. There were no issues and treatment was successful."

"One of the most positive things was being able to choose an essential oil to burn on the stone when the stem cells were being returned."

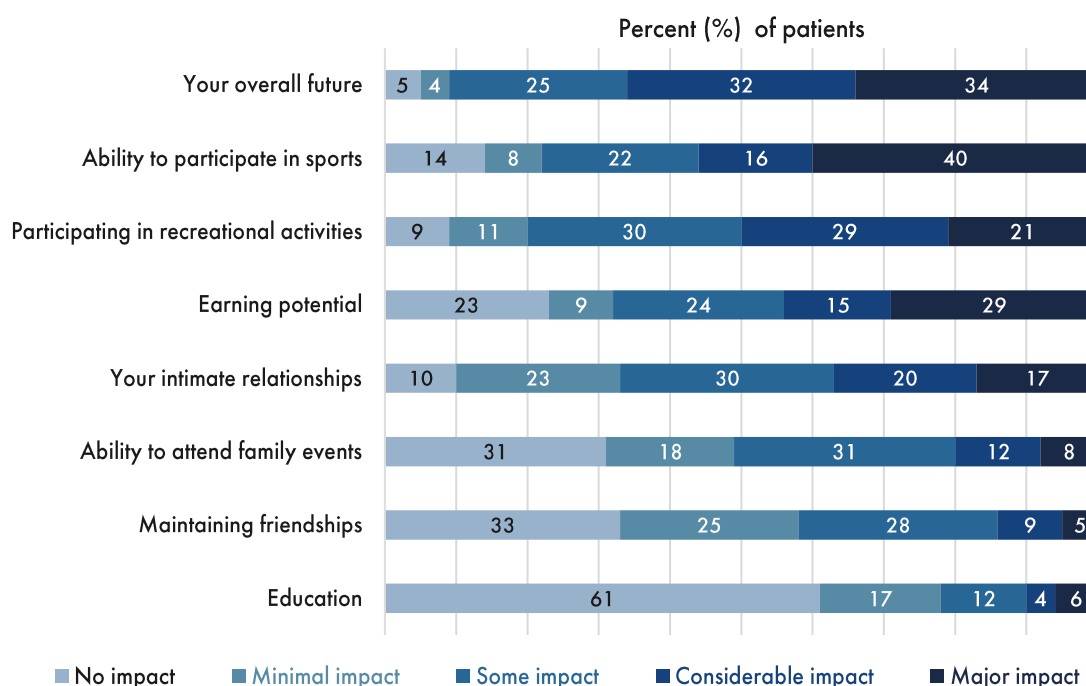
"Donated to self. Text book. Only problem has been the resulting excessive burping which continues after almost a year."

II QUALITY OF LIFE

For two thirds of patients having myeloma has had a major or considerable impact on their overall future. Around half struggle to participate in sports or recreational activities. The earning potential of 44% has been significantly affected, and the disease has had a major or considerable impact on the intimate relationships of 38%.

Figure 4 - Impact myeloma diagnosis has had on quality of life

Q -Thinking about your quality of life, what level of impact has your myeloma had on the following? (n=77 to 111)



Being diagnosed with myeloma has serious life-changing impacts. Patients, caregivers and family have to come to terms with a shorter life expectancy and the reality of no known cure, as well as fear, pain, the severe and debilitating side effects of treatments, and financial stress.



In their own words:

"My partner's diagnosis has quite radically changed our lives. From having active lives diving, boating, fishing etc, and with very good salaries, we sold everything and moved cities to be close to family for support. [My partner] had 2 years of no work and I took a \$15,000 annual salary drop in a new job, and my career has limited options here. We must plan everything around his ability to cope with pain and lethargy."

"Confusion, inability to communicate, muscle wastage, tiredness, constant sleeping, frustration, fear of the unknown, lack of understanding of what to expect."

"Suffered with side effects of the chemo. Lost 60kg in 6 months. 'Chemo brain' meant six

months of life lost. Decided to stop treatment and have quality rather than quantity but still suffering side effects of chemo. Wish we had more time at the beginning to think it over rather than being rushed into treatment. It has been a hard year."

"I have myeloma with cardiac amyloidosis. One year ago I was not sure if I would live 6 more months. Myeloma hit me and my family as hard as it gets."

"I have smouldering myeloma which has a real psychological effect – have it, but can't treat it. Like a ticking time bomb. My lovely daughter is devastated."

"Stressed, weak, tired, painful, debilitating, depression, vulnerable, irritable, sleeplessness, physical decline."

"Heartbreaking! Mum has worked hard to look after herself, eats well and kept active, only to be hit with this and the therapy that is needed, and she will need further treatment again in a year or two."

"Uncertainty for the future, not trusting people at work or employers, very, very agitated when on Dex, always aware of MM, scared at times and manage by trying to be busy."

"The biggest issue is the fact that there is no cure. You know that your life expectancy is less than it may otherwise have been."

"It has been life-changing. It turned our world upside down."

"It was a disease I had never heard of, and since I had led a very healthy lifestyle I was unprepared for a diagnosis of a terminal illness. I am in constant pain and my body has changed considerably i.e. with a shortened torso and a deformed back. I can't participate in many of the activities I used to enjoy and I have difficulty in managing household duties and gardening."

"I now have anxiety & depression. Family on edge when checkups are due. Financially stressed."

"I have had to come to terms with the fact that this is a severely life shortening condition. Earlier higher doses of Dex made me not a nice person to be around which affected family relationships. Downsized house six months after diagnosis to be debt free and in a financial position to be able to use the mortgage facility in a new lower-value home to pay for non-Pharmac funded drugs and overseas treatment. This is frustrating as I have a very comprehensive insurance program including Southern Cross Medical Insurance (\$60K p.a. for Pharmac funded drugs and \$10K for Med Safe approved drugs) which falls well short of the cost of the latest available drugs. I did get a \$50K Trauma payout on diagnosis as part of my extensive Life Insurance program. My condition has not triggered my Income Protection Insurance as I can work more than 10 hours per week. Currently working 25 hours per week."

Many describe heightened stress levels, falling self-esteem and confidence, feeling out of control and a loss of personal identity.



In their own words:

"Major impact. Stressful, socially isolating, the loss of partner/sharing. Impacts on one's own health as a carer due to the stress and fatigue. The loss of personal identity."

"I used to have control of my very busy life. I have lost control of that now. I look the same but my energy levels have changed greatly. I have to depend on others for many things. My family are very important and are wonderful to me. My dear friends are the same. But I know it's difficult for them."

"It's very stressful living with the disease, especially knowing it's incurable and many of the more effective treatments aren't available here in NZ."

"The drugs have caused me to have a different personality. I look good so people don't realise I am not the same person underneath the false facade."

"Not knowing my future is the biggest thing. For my family, the same. Not knowing if I will be around for them in the future, especially for my children. Not knowing how far in the future to plan, retirement funds etc. It has also affected me physically. I am not as able as I was before. You must get used to a 'new normal' as far as physical ability is concerned."

"Every check up has me worried that this is the one that I will get bad news again."

"I lost a lot of confidence and at times I am extremely anxious."

"Everyone knows that from the first day of diagnosis your life will never be the same but you don't know how it's not going to be the same. I had always had a busy well-structured life controlled by me and balanced between family work and recreation. As it was less than two weeks before the treatment started, haematology were all organised but we were in a fog. No support services offered and no clue about who to ask. Just an overall feeling of we must get this started NOW. So much wiser now. Told my direct family first, all gutted but loving and supportive. AND NOW I AM NO LONGER ON CONTROL."

Many patients and carers wrote about the stress on their relationships.



In their own words:

"I sometimes feel unable to do anything other than read, watch operas or sort photos. Multiple myeloma has turned me from a fit, active retired person into an old man."

"Low energy levels become frustrating, self esteem lowering. Occasional feeling that things/tasks don't matter any more. Strain on wife constant, relationship strain from time to time, low libido."

"It has had a major effect on my marriage, which ended 18 months ago."

But for some myeloma has brought a change in their perspective on life and for a few has taken them away from the 'treadmill of work'.



In their own words:

"I am still an eternal optimist. If anything the diagnosis has given me a greater appreciation for each day I am blessed with."

"It has made me think about life in general and possibly helped get me off the high pressure treadmill of work."

"Made us appreciate every moment now and to get out and do things. My husband has struggled the most and needed some counselling."

"It has totally changed my perspective on life. I used to worry and fret about the smallest of things, but now I just take things in my stride. Even when my residence was found to be a leaky home which will cost me around \$150k to repair, I'm now surprisingly laid back about it."

III THE FINANCIAL IMPACT OF MYELOMA

Impact on employment status

Over one quarter (27%) have had to leave full time work, many having to stop working or retire early. Over one third of patients/carers (37%) cite myeloma as having an effect on their change in employment status. However, almost as many (35%) say their diagnosis has had no effect on their employment status.

Figure 5 - Employment status current & prior to diagnosis

Q - Thinking back to before you/your dependent was diagnosed with myeloma, which of the following best describes your employment status: (n=120)

Q - And which of the following best describes your current employment status? (n=117)

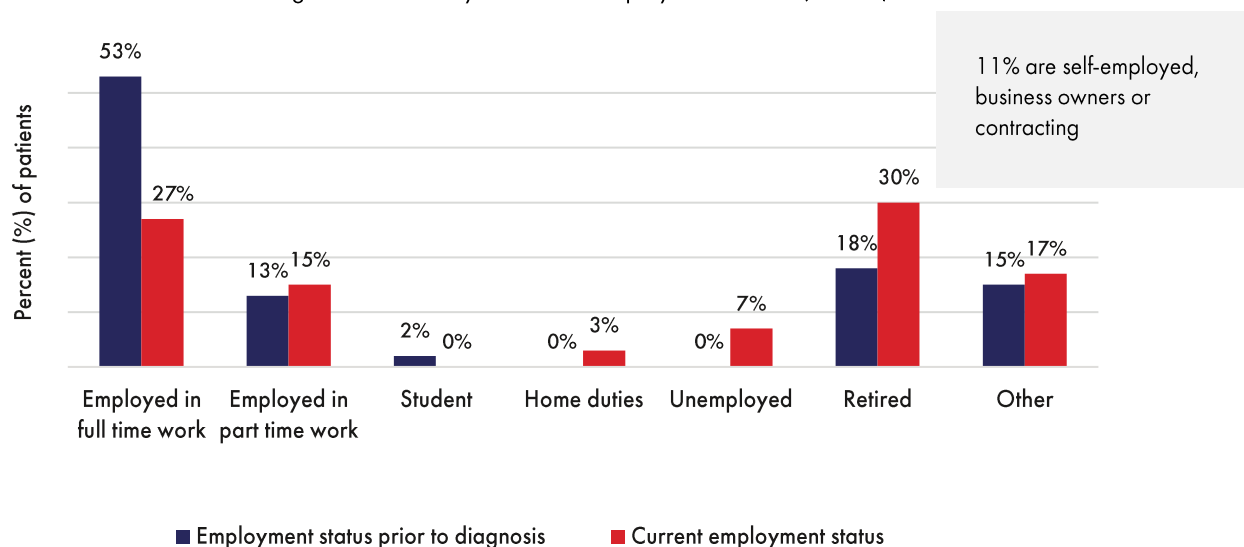
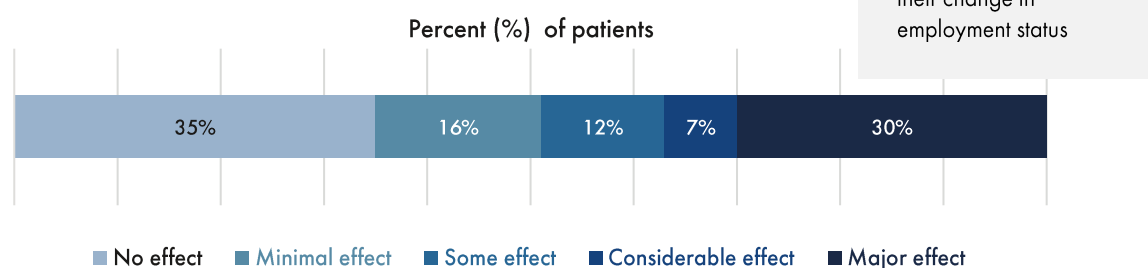


Figure 6 - Effect on employment status

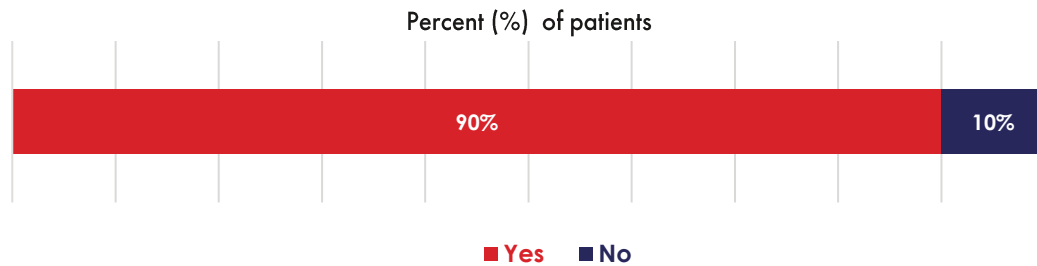
Q - What, if any, effect has your myeloma had on your employment status? (n=114)



Of those who were employed, 9 out of 10 patients and carers discussed their diagnosis with their employer.

Figure 7 - Discussed diagnosis with employer

Q - Did you discuss/have you discussed your condition with your employer? (n=77)



Employers were generally very supportive of patients and caregivers, many providing ample sick leave and, where needed, reduced or flexible work hours.



In their own words:

"Employer at the time of initial diagnosis was very accommodating and allowed me to go onto part-time work."

"Stressful, as the same day (immediately after) I told my employer, two staff were made redundant (in an office of only six employees). I was not one of them."

"I was totally open about it, both with my boss, his boss, and HR. The company was fantastic, and I'm sure my openness was in part the reason they supported me so strongly by protecting my job while I was off-work for 10.5 months, and allowing me huge latitude in a very slow return to work over another 10.5 months while recovering from my ASCT."

"I was open with my past employer and my team and they were very supportive. Because I am in deep remission, I've only told a few people at my current work because it does not affect anyone there."

"Employer supportive, no impact on career other than of my own choosing. I decided that my condition was not confidential. Found it easier to deal with by being transparent."

"Full discussion with employer and I was on unlimited sick leave for the majority of my first line of treatment. Three months after SCT graduated a return to work was recommended but this wasn't well managed and I returned to full time work in a high pressure job, possibly sooner than I should have. Did the role for a further three years but early signs of disease progression and increasing work pressure lead to my decision to resign."

"Decided to call a staff meeting and make an announcement to all my team at the same time so they would all get the same info. We all know how dangerous 'Chinese whispers' "

can be but there is no way of completely avoiding it. Still it was a hard thing to do, very emotional, but I'd do the same again."

However a few employers proved to be unsympathetic or inflexible.



In their own words:

"Discussion resulted in termination of my employment."

"Employer didn't really understand what I was going through. In hindsight, the Dex I was on at the time had a major impact on my ability to function at a high level at work. Was 'restructured' out of my role about 26 months after diagnosis."

"My employer was very unsympathetic and provided very little support for me or my partner."

"Employers seem mainly interested in the impact of treatment on energy levels."

"They were sceptical about hiring me."

Patients and carers who had their own businesses or were self employed were hard hit.



In their own words:

"At the time my husband and I owned a business. We had to sell the business at a huge financial impact which put us under enormous pressure in addition to finding out he was seriously ill."

"I am in partnership with my own business which had to be closed for 5 months."

"Have turned down 3 short term contracts ...will not be returning as it's a high stress role."

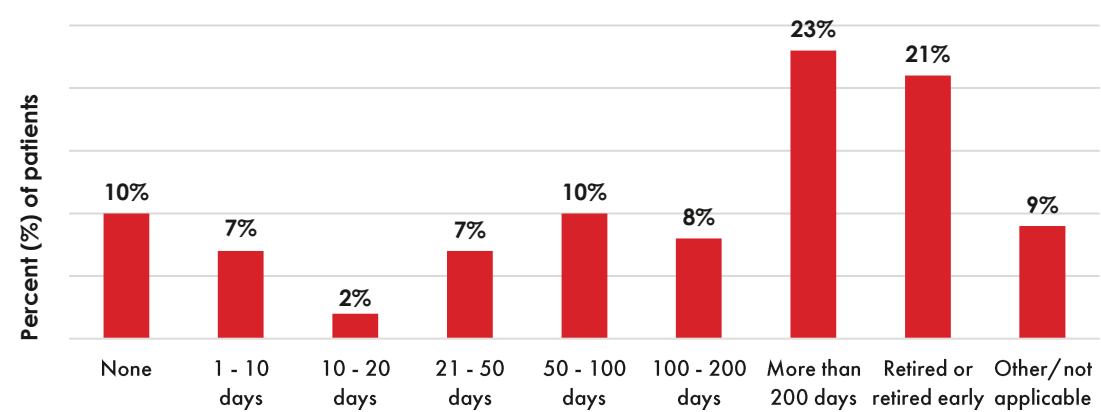
"Had my own small business. Had to sell at end of lease as it did not pay enough for me to employ another staff member."

Absences from work

Almost a quarter of patients/carers (23%) have missed over 200 days of work since their diagnosis, significantly affecting income and increasing stress levels. One in 5 were already retired or retired early (21%).

Figure 8 - Average number of days off since diagnosis

Q - How many days' absence from work have you experienced? (n=108)



*Note: mid-point taken for each answer option to create a rudimentary average. Average number days off work per year were calculated by dividing the total number of days by an average length of diagnosis in years.

**101
DAYS**

The average number of days a patient or caregiver has had to take off overall since diagnosis*

**32
DAYS**

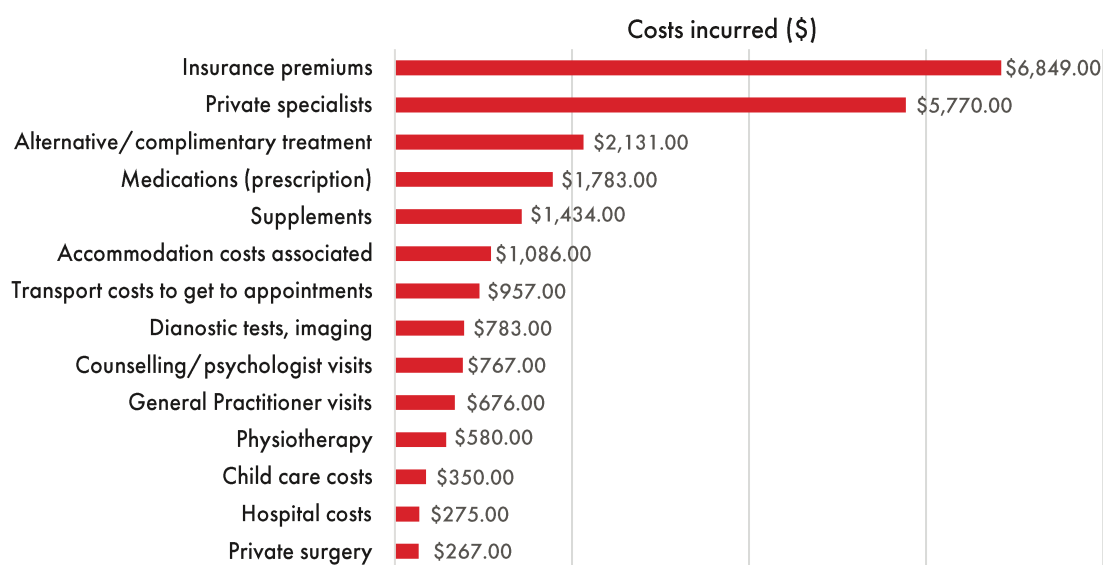
The average number of days a patient or caregiver has had to take off work per year since diagnosis*

Costs

Insurance premiums (\$6,849) and the costs of private specialists (\$5,770) are contributing the most to the increase in patients' costs due to myeloma diagnosis. Patients have spent on average over \$2000 on alternative treatments, close to \$1800 on medications and prescriptions, and nearly \$1500 on supplements. Indirect costs such as travel and accommodation are over \$2000.

Figure 9 - Estimated average cost of myeloma*

Q - What costs have you incurred due to your myeloma? Please think about the estimated total cost for each of the options below:



* Note: average costs calculated from those who gave a numerical response. An average annual cost was calculated by dividing the total cost to date by an average length of diagnosis in years. Base size reduced. (n=91)

\$7,598

The average amount a patient spends
in relation to their myeloma

\$101,579

Average estimated Loss of Earnings
since myeloma diagnosis

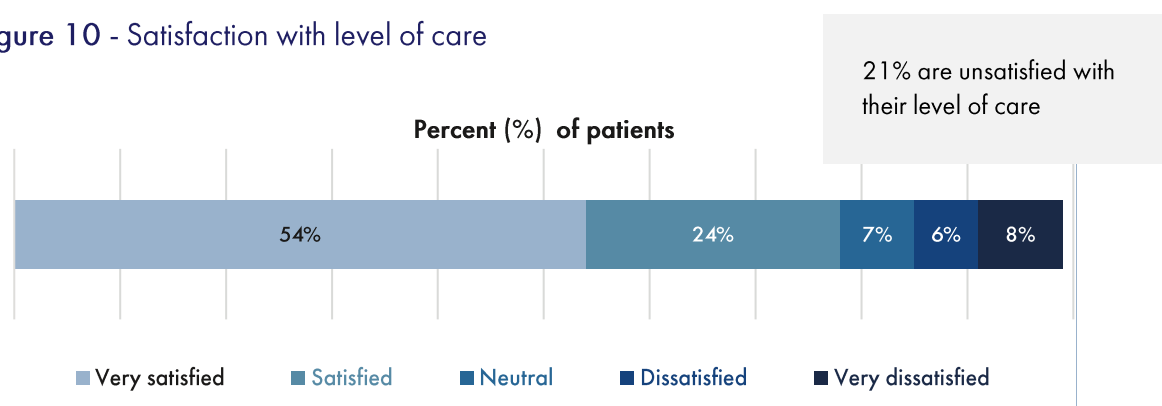
The average amount a patient or caregiver has spent annually in relation to myeloma is approximately \$7,600. Coupled with that is a large drop in income as they have had to reduce or stop working. The estimated average loss in income of a myeloma patient since their diagnosis is over \$100,000.

IV LEVEL AND QUALITY OF CARE IN NEW ZEALAND

Most patients/carers (78%) feel satisfied with the overall level of care they have received and 21% are not satisfied. There is lower satisfaction regarding the quality of myeloma treatment available in New Zealand, with 42% agreeing it is currently of very high quality, but almost a third (30%) feeling it is average or of low quality.

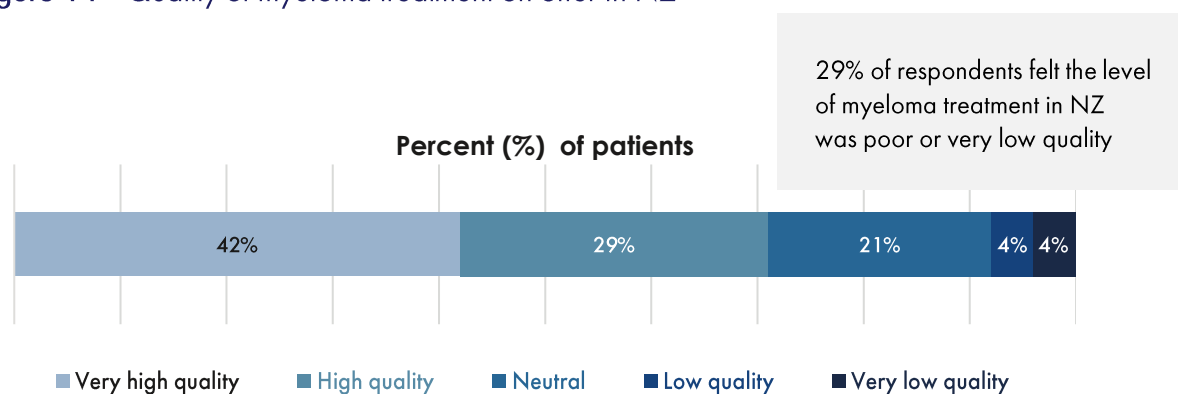
Overall level of care

Figure 10 - Satisfaction with level of care



Quality of treatment

Figure 11 - Quality of myeloma treatment on offer in NZ



Availability of myeloma information

Most myeloma patients/carers (76%) are happy with the information available on myeloma in New Zealand, however 24% are not satisfied, with the major areas of need for more information being research (30%), treatments (26%) and clinical trials (23%).

Figure 12 – Satisfaction with availability of myeloma information

Q - Overall, how satisfied are you with the myeloma information available to you? (n=101)

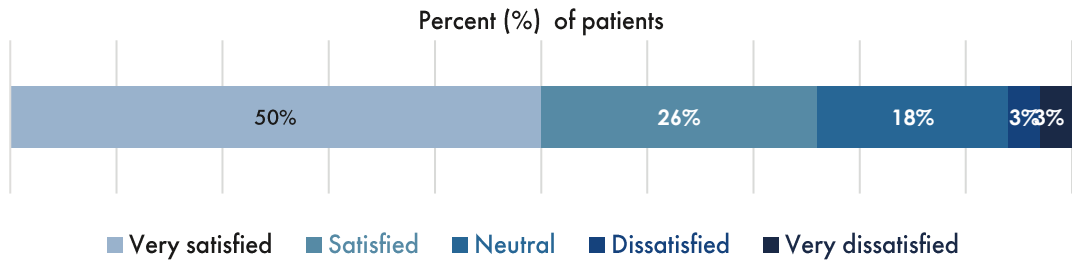
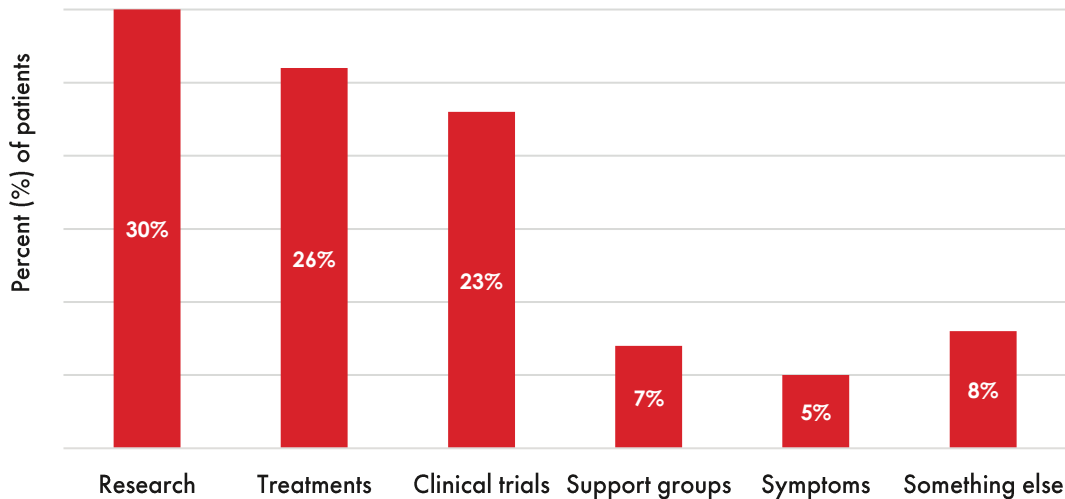


Figure 13 - Areas for more information

Q- From the list below, what is one thing you would like more information about? (n=99)

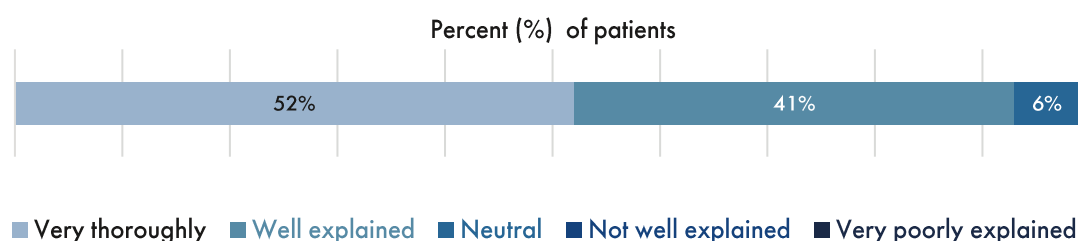


Treatment explanation

Medical professionals appear to be doing a good job in explaining treatments and procedures, with 93% of patients/carers feeling these were well or very thoroughly explained before being administered.

Figure 14 - Thoroughness of treatment explanation

Q - How thoroughly were your treatments explained to you prior to their being administered? (n=99)



Those who felt treatments were not well explained said they were rushed into treatment after diagnosis, before they had had time to fully understand what was going to happen and what side effects were likely.



In their own words:

"We were given books to read and an appointment two days after the results to get chemo underway and no thorough follow up. The specialist treated my husband like a test dummy and I am upset that loss of weight and other side effects were not addressed when they should have been. We were on this train-ride and there was no other route or option or timeframe given."

"Too quickly done."

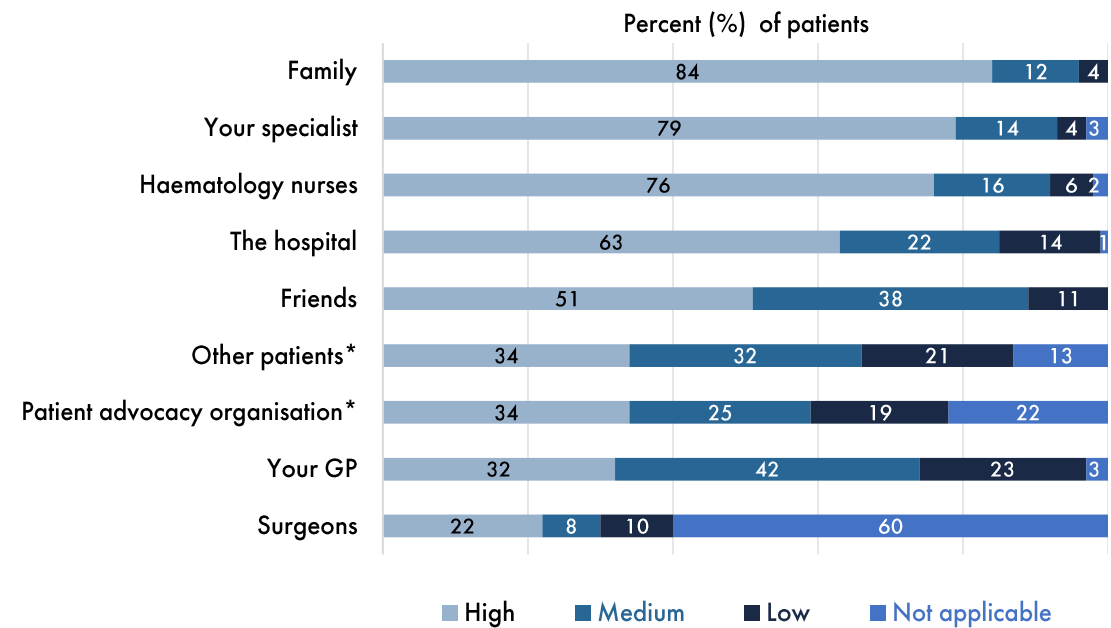
"Only had one discussion so far... telling me I have MM and they want to start treatment next week. Orientation to explain the treatments with the nurse will be in two days time."

Support

Patients and caregivers highly rate the level of support they receive from their family (84%), their specialist (79%) and their haematology nurse (76%).

Figure 15 - Level of support

Q - Thinking generally about the support you have received following your diagnosis with myeloma, how would you rate the level of support you’ve received from...? (n=112)

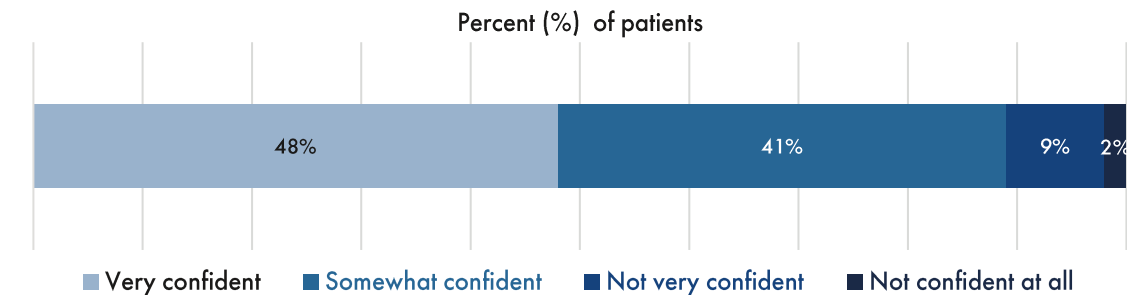


Understanding myeloma

Over half (52%) of myeloma patients or caregivers have at least some level of doubt about their understanding of their condition.

Figure 16 - Confidence in understanding my condition

Q - How confident are you in understanding your condition? (n=110)

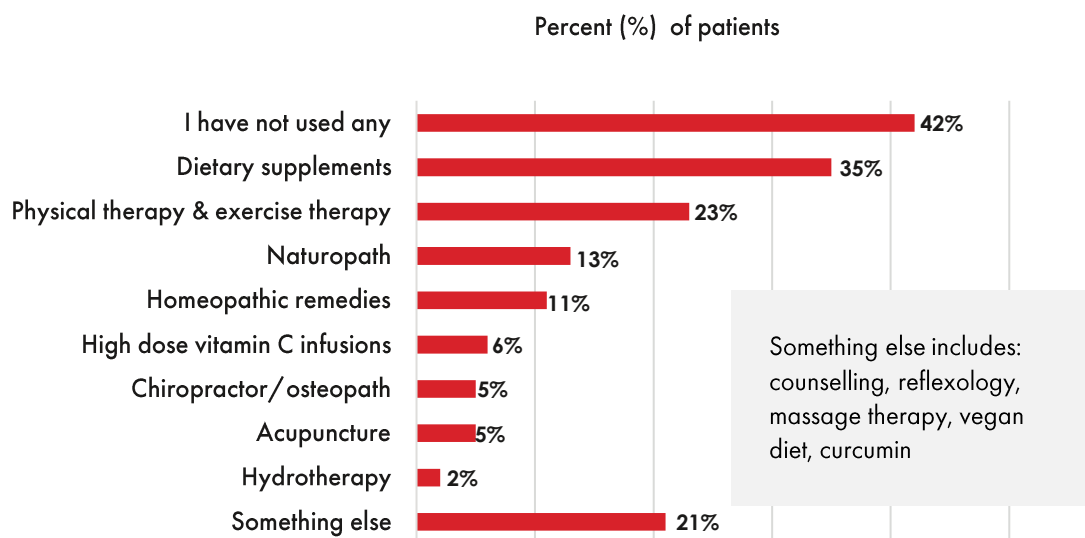


Alternative or complementary therapies

The majority of patients (58%) have tried an alternative or complementary therapy, the most common being dietary supplements (35%) or physical/exercise therapy (23%).

Figure 17 - Patients use of alternative or complementary therapies

Q - What, if any alternative or complementary therapies have you used to help in your diagnosis of myeloma? (n=103)



From those who tried alternative or complementary therapies there are mixed reports. Some found them helpful, sometimes very helpful, in managing their symptoms, mental health, energy levels or reducing pain. Some patients are finding cannabis helpful. Many felt keeping active and just 'doing something' helps maintain a positive attitude. Others were more sceptical or unsure of any benefit. Some patients still just felt very lost, tired and in need of more support and advice.



In their own words:

"Specialist exercises help to build strength in the areas that have been impacted by broken and damaged bones (spine and collar bone)."

"Acupuncture helped with neuropathy and supplements help keep his immune system healthy."

"I believe the Gawler principles kept the myeloma stable for 10 years without medication."

"They have helped me to manage the symptoms and made life more comfortable."

"Turmeric and ginger for inflammation has helped. Magnesium for sleep also helps. In Dargaville you do not have many options and no one here really wants to help except for the hospice. Physio and GP say they are not aware of this problem so they have been of little help."

"Chiropractor helped with back pain. Supplements helped with neuropathy."

"Good for the mind."

"We had to fight to get a walker plus other equipment that in the end the hospice sorted."

"No idea, it just feels good to do something that might help."

"Walking – achievable and uplifting."

"Excellent – especially medicinal marijuana."

"Pilates, walking, watching the daffodils coming up. Projects include buying a new car, and my own 'distraction therapy' cooking after chemo each week."

"Chiropractor helped with backpain. Supplements helped with neuropathy."

"There has been no advice on any alternative treatment. My Mum is on so many prescribed pharmaceuticals that she doesn't want to take another thing and there is absolutely no support from the orthodox medical system she is being treated by to provide any information on alternative/supplementary treatments, even though we have asked. We are just so tired. This disease and this process just wears you down and you feel you don't have a voice."

"I don't know if they made a difference or not. I feel diet and supplements are beneficial as so far I have remained in VGR and in good health."

"High dose vitamin C perhaps not so much, but a regimental diet and various nutritional supplements have been a massive boost to maintain good health and minimize side effects. It's possible some have provided synergistic anti-cancer effects alongside treatments as well (e.g. curcumin)."

"I take turmeric and cranberry. I was constantly getting UTIs and haven't had one in 2 years of taking cranberry."

"I saw a Chinese doctor for one year during remission and I feel the herbs prescribed helped with supporting my liver and immune system. I did not want to spend money on supplements without a good understanding, so I saw a naturopath and we put together a regime. I have a regular yoga practice from an experienced teacher and use regular meditation including sound therapy."

V AREAS FOR ACTION/MORE SUPPORT

Myeloma patients and carers want information about latest treatments and clinical trials, advocacy for new treatments, seminars with experts, support and connections with others going through the same journey, and training and support for carers and families.

The majority of comments concerned the need to advocate with government for funding new treatments.



In their own words:

"Continue to advocate for advanced treatments with the government and supply patients with up to date treatment knowledge in a way we can understand them."

"Info on new treatments that are available and how to access them, and new drugs and how to access them."

"Given other organisations in this space, I would like this organisation to deal with factors not addressed by the others, such as advocacy with government on wider cancer issues also of concern to MM patients."

"Lobbying government on behalf of myeloma patients for access to new therapies, etc."

"A voice in the system to get new treatments subsidised in NZ."

"Earlier advice about overseas options for treatment not available in NZ."

"Pharmac needs to be jolted to the real world of medications available for people with cancer."

"Advocacy for new drugs with Pharmac."

"Are there any trials I can be eligible for? I would like more information relative to NZ patients. What options are there overseas which we do not have, and are these options likely to be available in NZ eventually?"

There is a strong desire for simpler, more comprehensible information about tests and treatment pathways, more advice about what to expect as the disease progresses, and a guide to all the support services that are available.



In their own words:

"I would like to sit down with one person and do a flowchart that explains all the tests & terminology on one large sheet of paper that pulls everything together."

"I'm not sure where the responsibility lies for this but it would be great if some organisation could produce a document that gives a patient full information of ALL the support agencies available - medical, educational, social, financial, support groups. I know we are given a big bag with all sorts of information but it is overkill at a time when your brain is already mush. Perhaps a very cleverly designed easy to read Flow Chart type opening coversheet, followed by a clear step-by-step one-pager outlining the

services and contact details for each of those on the cover sheet. This would provide us with a helpful welcoming pack."

"A readily accessible glossary on the website of all the medical acronyms could help us newbies."

"I realise that MM is different for everyone, but a list of what to expect in the first six months? What to expect should the patient decide to cease chemotherapy? i.e. how long will they live?, what will the pain levels be like? As a carer it would be nice to know in advance just how tired one can get, there appears to be very little in the way of written information available."

"What interests me is life expectancy. I know everyone is different and whilst all contributing to an average probably no one is the average. Local data still seems to trot out that 44 months is average with Stage 2 diagnosis and I do understand that a specialist is reluctant to be drawn on this. I am now 58 months. I can't believe that there is not reliable NZ data that could map age, gender stage of diagnosis and life expectancy. This is important for two reasons: balance of life planning and financial. I still have life insurance that is now proving costly relative to age and sum insured and I need to be able to weigh up the cost-benefit on a more informed basis."

More seminars around the country including the regions from experts on an array of subjects would be welcome. Topics should include latest international research, advances in treatment, the various phases of myeloma, training for carers, pain levels and management, question and answer sessions (preferably online), mental health issues, and the opportunity to meet and talk with other myeloma patients and carers.



In their own words:

"Better emotional support and greater resources on providing hope. It was traumatic being diagnosed and there was no support other than see your specialist in 2 weeks. Hope is part of the treatment!"

"It may be helpful to know how many others are in my geographical district, not just to get together and talk about our conditions but also maybe to brainstorm how we can still be collectively useful in society/our communities even if we are immune suppressed, and some sociality for better mental health."

"Seminars on upcoming treatments that are becoming available."

"Guidance on sperm/egg banking prior to chemo."

"Training for caregivers and family separately from patient – what to expect, how to handle illness and emotions, where to seek help if needed. Seeing a physically ill person can easily be dealt with, but the Dex emotional outbreaks is something not many people can handle or understand. This causes family and friend relationships to crack because people don't understand what the patient is going through."

"More seminars with experts. More availability of psychologist specialists."

"Seminars to assist in regaining physical health and fitness."

"I've been disappointed with the pain management available (severadol) and would like to see medicinal marijuana legalised."

"Talking to other patients about their journeys going through different stages of treatment is so beneficial to us. Hearing from anybody who's walked in these shoes and what they went through helps you know what to expect."

"It would be good to be kept up with international trends without having to scan the internet."

"Probably just reassuring my family that I'm ok and that it's ok for them to worry or to be scared as that is natural. I don't look at myeloma as a burden; I see it as a crappy card that you get dealt in life. But no one knows when your time's up except for God so continue to live your life, love it and enjoy the time you have with your loved ones. Make amazing memories, don't look back on the past or dwell on any regrets you may have. Live in the here and now."

VI ADVICE FOR THE NEWLY DIAGNOSED

Patients offered many tips for the newly diagnosed: don't panic, stay positive, take one day at a time, be very well informed about myeloma and the treatments. Connect with others like you and take advantage of any support, assistance or information you can.



In their own words

"Grow your understanding of the disease, build a strong relationship with your specialists and nurses, and plan for a long journey. Be open about your needs so you can create sustainability in employment, and have your family and friends to support you on the journey. If you can, be kind and appreciative of everyone (even though you may be in pain, fatigued and depressed at times!)."

"Continue to live your life. Don't let myeloma rule you. There's support out there for you, you're not alone."

"Take the best possible treatment on offer."

"Ask questions and don't back down until you get the answers you want and get the answers properly explained in common language, not medical terms that can't be understood."

"Have a notebook with you and write everything down."

"Stop, sit and take time to ask what are the other options. Do not be railroaded into chemo. Ask the specialist to take time to discuss this with you and not, here are the results and this is what you're going to do."

"Don't be scared to join a support group. They are not there to mope around or feel sorry for one another - in fact they make good friends, are positive and help one another stay healthy. Through good diet, keeping positive, and ensuring your family understand what you'll be going through and how they can perhaps help during and after treatment - get them involved where and when they can be."

"Take it one day at a time. Get used to needles."

"Get as much information about your disease and treatment plans as you can before you agree to start treatment. I got the impression that treatment MUST start ASAP and felt pressured so I agreed. However, when I asked further down if it would have made any difference to wait a bit I was told no, so figured waiting an extra week to process and also to get organised to handover at work would have had me in a better place emotionally to start. I find my local haematology clinic amazing, I have had excellent care overall, but not as holistic as it could be "

"There's a myriad of drugs available to help manage your condition and with luck allow you to live for a very long time. Hopefully a cure will be found in your lifetime."

"Don't Google it, don't believe everything you read. Everyone's journey is VERY different - listen to their stories/advice but it may not all be right for you. Listen to your health

professionals. Listen to your body. Rest."

"It's a long road and there will be some new normals, but it is not necessarily a death sentence."

"Be brave. You can fight this with help. Join the support groups, they really help."

"1. Keep your data results and record them, so you have an understanding. 2. Have a person with you at the important meetings. 3. Don't let things get on top of you – keep in the moment."

"Have faith in the health system and the support. Be patient in recovery, be thankful for everything and everyone, live a normal life but reduce things you know are not helping recovery. Accept what you have but look for new things that you can do and achieve."

"Don't panic! The prognosis looks bad on the internet but it depends on your age and type."

VII RECOMMENDATIONS

1. Better mental health and emotional support

Patients and carers need better preparation and access to support throughout the treatment process, particularly when undergoing difficult procedures (such as SCT). This includes:

- i. Access to counselling and mental health support
- ii. Ways to connect with other patients and support groups and access to agencies that can provide assistance, and
- iii. Training for caregivers, particularly in coping with patients' depression and mental health issues.

2. More intelligible, more timely information

Patients and carers need information presented in a way that is easy to understand, and at the right time, so they can process it along with everything else going on in their lives. This includes information and expert talks and seminars about:

- i. the disease, its potential path and survival rates
- ii. current and new treatments
- iii. compassionate access programmes, and
- iv. clinical trials and research.

3. Advocacy for new treatments

Myeloma NZ and other related patient groups should actively advocate to the Government to fund new treatments and facilitate the opening of more clinical trials and access programmes.

4. Education of medical professionals on myeloma

Better education of GPs and medical professionals to improve understanding of myeloma is critical. Upskilling doctors at the frontline should lead to earlier tests and earlier diagnoses.

5. Greater public understanding of myeloma

Patients and carers would also like to see information programmes that generate greater public understanding and awareness of myeloma.



© Myeloma New Zealand 2019
Published by Myeloma New Zealand
Registered Charity No. CC53924
PO Box 25162
Wellington 6011
New Zealand
www.multiplemyeloma.org.nz

ISBN: 978-0-473-48524-5 - print
ISBN: 978-0-473-48525-2 - online/PDF