92-year-old joins myeloma study to help make a difference

Iris Dutton is determined to help other patients living with myeloma. The 92-year-old was diagnosed in 1999 and has been living with myeloma for the past 15 years. Over this time she has been actively monitored at Middlemore Hospital. Recently Iris opted to take part in a clinical trial known as the Millennium Study.

Iris, who lives in Pakuranga in Auckland, says she hopes the results of the study will help others diagnosed in the future.

“My rationale is that I’m going to leave this life soon, but I’ve done something to help people who are diagnosed, I feel like they get a raw deal,” she says.

Iris believes being of assistance to others is one of the key things keeping her motivated.

“I never had parents of my own. I was handed over to the State, but my carers were kind and that’s made me want to also be kind to others.”

The road has not been easy for Iris. She was widowed at 24 when her husband passed away in an accident leaving her with her four-month-old son Rob to care for. Eight years later she remarried and had two more children named Christine and Simon. The mother of three first found out she had myeloma after she participated in a trial in 1999.

“The study involved having to do a blood test. I did the test then later handed in my form to the administrators and they told me to visit my doctor.”

Iris was diagnosed with myeloma and was prescribed oral chemotherapy to help treat it. Her myeloma was reasonably stable for several years until 2012, when it became more aggressive causing anaemia and making her bones weak and painful.

“I’ve had more than one type of treatment since I was diagnosed. In December last year I was told about the Millennium Study, I joined later than anyone else, but it’s been four to five months and I’ve been doing very well,” says Iris.

The study compares different drug combinations - oral MLN9708 plus lenalidomide and dexamethasone versus a placebo plus lenalidomide and dexamethasone in adult patients with relapsed or refractory multiple myeloma. Lenalidomide is in the same class of drugs as thalidomide, which is often prescribed to myeloma patients for treatment. Dexamethasone is a steroid which works in combination with the other drugs to enhance the killing of myeloma cells. These two drugs are prescribed to all patients in the study, but what changes is whether they are prescribed with an additional oral drug currently known as MLN9708, or a placebo.

The aim of the study is to find whether MLN9708 helps with long-term survival for myeloma patients, and if patients receiving the drug do significantly better than those on placebo. The study also aims to confirm that MLN9708 is safe, as shown in early non-randomised trials.

For Iris, the trial has delivered fantastic results. Her blood results are the best she has had in the past 10 years. She is currently in partial remission.

Iris says that although the treatment has some minor side effects she overcomes them by staying active.

“I could stay in bed all day and do nothing, but I like to walk around and get my daily exercise. I keep going and keep walking because I feel like that’s part of enjoying life.”

Iris is very close to her six grandchildren and her great granddaughter who all help keep her on her toes.

“One of my grandchildren is studying at Otago University and we’re very good friends,” she says. “My oldest son Rob came over from Australia with his children and granddaughter for a holiday, so at one point there were four-generations of our family all together.”

Iris is also part of Probus, an organisation for retirees who like to keep active and volunteers as a St John caring caller.

“It gives you a lot of satisfaction when you can help someone,” she says.

Myeloma isn’t the only health issue Iris is facing. She has macular degeneration in her eyes, which results in the loss of her central vision, and also wears two hearing aids. She says it’s just something to deal with.

“The nurses at Pakuranga Park Village are very good at taking care of me and making sure I have my medication. My daughter Christine is also very helpful and takes me to the hospital every month,” she says.

Clinical trials can give access to new and unfunded medicines. Patients who are in clinical trials can have better outcomes than those who are not. They receive very close supervision necessary to document the study.

The Millennium Study is now closed, but for information on other myeloma clinical trials please see the ‘Clinical Trials’ section at the back of this publication or ask your haematologist if there is a trial for your condition.
Support Services

2014 Blood Cancer Patient Forum

The team at Leukaemia & Blood Cancer New Zealand are excited about hosting the next Blood Cancer Patient Forum on Saturday 13 September 2014.

The Blood Cancer Patient Forum is a unique opportunity for patients to hear international and local speakers discussing a wide range of topics relevant to New Zealanders living with blood cancers and related conditions. Family/whānau and friends are encouraged to attend. Alongside the learning it is a great opportunity to meet people in similar situations.

There will be a number of sessions ranging from disease biology to treatment updates, new research and mindfulness sessions.

One of the world’s foremost human geneticists and leukaemia researchers, Professor Stefan Bohlander from the

What is a full blood count?

People living with myeloma experience many blood tests, especially when first diagnosed.

The Leukaemia & Blood Cancer New Zealand Support Services team are often asked what the results mean, so we have explained some of the most important components of a full blood count below.

One of the most common tests ordered is a full blood count, which is sometimes called an FBC or a complete blood count.

Red blood cells (also called red cells) are disc-shaped cells that carry oxygen around the body. They do this via a molecule contained in the red blood cell called haemoglobin (Hb). A lack of haemoglobin is defined as anaemia. If you are anaemic, you may be short of breath, pale, and tired. However, anaemia due to low haemoglobin is not the same thing as iron deficiency anaemia.

The normal haemoglobin range for a man is between 130 – 170 g/L (grams per litre), and the normal haemoglobin range for a woman is between 120 – 160 g/L.

Haematocrit is the name given to the proportion of the blood that is occupied by red blood cells. A low haematocrit suggests that the number of red blood cells in the blood is lower than normal.

The normal range of the haematocrit for a man is between 40% – 52%, and the normal range of the haematocrit for a woman is between 36% - 46%. This is also referred to as packed cell volume (PCV).

White blood cells (also called white cells or leucocytes) are cells that fight infection. There are many different types of white cells which fight infection together in different ways, including neutrophils, eosinophils, basophils, lymphocytes and monocytes. In this article we will focus on neutrophils as these are the type of white cells that are often talked about when people have a diagnosis of a blood cancer.

The normal white cell range for adults is between 4.0 – 11.0 x 10⁹/L. This means there are between 4,000,000,000 and 11,000,000,000 white blood cells per litre of blood.

Neutrophils are the white blood cell that fight bacterial infections. The normal neutrophil count for adults is between 2.0 – 7.5 x 10⁹/L. If your neutrophil count is less than 1.0 x10⁹/L, you are considered to be neutropenic and at risk of developing frequent and sometimes severe infections. If you have recently had chemotherapy you will have been advised about safety precautions during periods of abnormally low counts of neutrophils, also known as neutropenia. It is very important that you advise your treatment centre immediately if you develop a temperature of 38 degrees Celsius or more or feel generally unwell, as this can become life-threatening very quickly.

Platelets are cells that circulate in the blood and play an important role in forming blood clots to stop bleeding. The normal adult platelet count is between 150 - 400 x 10⁹/L. When platelet counts are very low, a person may experience bruising without an apparent cause, or bleeding that doesn’t easily stop, for example a persistent nose bleed.

Transfusions of red cells or platelets may be offered during treatment for blood cancers. These are usually given to ‘top-up’ blood counts while the bone marrow, the body’s blood cell ‘factory’, recovers from chemotherapy.

Please be aware that normal ranges for each blood count vary slightly and those mentioned here may be different from the ones used at your treatment centre. The normal ranges mentioned here are for adults. Please ask at your treatment centre for normal ranges for children.

If you would like to know more or have questions about your blood test results, please feel free to contact our patient Support Services team on 0800 15 10 15, or info@leukaemia.org.nz.
Understanding benefit changes

A number of changes to the New Zealand welfare system have now come into play. They affect a variety of benefit categories including the sickness and invalid benefits and often can be a little confusing to understand. People who were previously receiving a benefit have been automatically transferred to the new system, but it’s important to have the right information to help make the process easier.

Sickness benefit now tracked to getting you back into work:

Those previously on the sickness benefit are now on ‘Jobseeker Support’. This benefit type is particularly focused on supporting people back into work. It is a category that includes both people who can work either full-time, part-time, or those with a health condition or injury that temporarily prevents them from working. You will need to reapply for this benefit every year (after 52 weeks), or when your medical certificate is due to expire.

There are no changes to what is required in your medical certificate. You will simply need to visit your GP to obtain it and get it renewed before it expires. Benefits are usually cut when a medical certificate expires, so you need to be proactive about getting it renewed.

While this benefit is geared towards getting people back into the workforce sooner rather than later, Work and Income clearly states in its fact sheet that if you are physically unable to work, and your supporting medical documents prove this, then you should not be asked to look for a job. This is particularly important to note for blood cancer patients.

If you receive Jobseeker Support you may still be asked to meet with a case manager to talk about when you may be able to return to work, and what work you may be able to do. There are also other benefits catered to those who may be out of work indefinitely.

The benefit for long-term support

The Welfare Reform Factsheet and Q & A document states, “those who are permanently or severely disabled, severely mentally ill, or terminally ill, will be fast tracked into the Supported Living Payment.”

The Supported Living Payment benefit is assistance for people who have, or are caring for someone with a health condition, injury or disability. You may be able to get the Supported Living Payment if you are:

• permanently and severely restricted in your ability to work because of a health condition, injury or disability, or
• totally blind, or
• caring full-time for someone at home who would otherwise need hospital-level, or residential care (or equivalent) who is not your husband, wife or partner.

If you have a partner, their situation will be considered in your application. It’s best to talk to a social worker or case worker to see what you are eligible for.

Work and Income says to get the Supported Living Payment because of a health condition, injury or disability, you must be:

• permanently and severely restricted in your capacity to work because of a health condition, injury or disability. This means you:
• have a condition affecting your capacity to work for more than two years, OR
• have a life expectancy of less than two years AND
• can’t regularly work 15 hours or more a week in open employment

As part of your application for Supported Living Payment, Work and Income may ask for additional medical information that confirms your condition and the impact it has on your ability to work. Work and Income may refer this information to a Regional Health Advisor. This is a Work and Income employee responsible for providing advice and recommendations on health factors associated with benefit applications and the appropriateness of services.

Other forms of support

There are many other support payments available through Work and Income including disability allowance to help with the ongoing costs resulting from a health condition or disability, accommodation assistance, and receiving a community services card, which subsidises some health services and prescriptions.

Pharmacies also provide a free Pharmaceutical Subsidy Card (PSC) through the Ministry of Health. This allows the cardholder and named family members to pay a lower amount on government prescription charges and a maximum of $100 on prescription charges in any one year. Best of all there is no income testing for the PSC, so anyone can get it.

Dealing with finances post-diagnosis can be extremely difficult. We recommend getting a social worker to advocate for you. For more information, or if you have any questions feel free to contact our Support Services team on 0800 15 10 15. For more information about assistance available from Work and Income please visit www.workandincome.govt.nz or call 0800 559 009.
More support at Wellington Hospital

Kelly Harrison is a name to know for myeloma patients heading to Wellington Hospital. She is the Clinical Nurse Specialist in the haematology team who works specifically with people with myeloma.

Kelly is often the main point of contact for myeloma patients at the hospital. Her role is to make patient care as seamless as possible and is there to answer any medical questions about treatment or continued care.

“What I’m working towards is that patients have a point of contact through me and with my contact details,” says Kelly. “I can then touch base on the phone, text message or email. I also see patients when they are in for treatment and I’m available to meet them if they want to discuss medical concerns at any time.”

Kelly says her team is in the process of developing new protocols to help make patients’ treatment run smoother.

“We’re trying to arrange ways to save patients from making multiple trips into the hospital,” she says.

These initiatives include running standard health check-ups while patients are already in for treatment, as opposed to scheduling separate appointments. In the Wairarapa they are introducing subcutaneous chemotherapy for patients to avoid additional trips into Wellington.

Kelly also works with LBC’s Wellington Support Services Coordinator Sarah Brewer to help patients get the best possible care. Patients that need more information, or social support to manage the realities of a myeloma diagnosis, are referred to Sarah to help ensure their needs are met.

Currently there are more than 100 myeloma patients being seen in the Wellington region.

Kelly works alongside the consultants in the Myeloma clinic, which runs every Monday afternoon. To contact Kelly please call Wellington Hospital general enquiries on (04) 385 5999.

Clinical Trials

LBC supports participation of patients living with myeloma in clinical trials. It has been shown that involvement in clinical trials improves quality of care for patients and may allow them to access cutting edge, potentially life-saving and life enhancing treatments.

The following are trials in myeloma currently recruiting in New Zealand as of February 2014.

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<thead>
<tr>
<th>Hospitals</th>
<th>ACH: Auckland City Hospital</th>
<th>CHCH: Christchurch Hospital</th>
<th>DUN: Dunedin &amp; Southland Hospitals</th>
<th>MMH: Middlemore Hospital</th>
<th>NSH: North Shore Hospital</th>
<th>PNH: Palmerston North Hospital</th>
<th>SSH: Starship Children’s Hospital</th>
<th>WAI: Waikato Hospital</th>
<th>WLG: Wellington Hospital</th>
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<tr>
<td>CLARION</td>
<td>A randomised study for patients with newly diagnosed myeloma. Looks at treatment with: carfilzomib, melphalan and prednisone versus bortezomib, melphalan and prednisone in patients who are not eligible for autologous stem cell transplants. Open at ACH, CHCH, NSH and WLG.</td>
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<tr>
<td>ENDEAVOUR</td>
<td>A randomised study for patients with relapsed myeloma. Treatment is either carfilzomib or bortezomib and dexamethasone. Open at ACH, CHCH, DUN MMH and NSH.</td>
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<tr>
<td>AMGEN 20090482</td>
<td>Randomised study of denosumab versus zoledronic acid (Zometa) in the treatment of bone disease in patients with newly diagnosed myeloma. Open at ACH and CHCH.</td>
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Our mission is to care, our vision is to cure

LBC is committed to improving the quality of life for patients and their families living with these blood cancers and conditions by:

• providing personalised patient support services,
• funding research for treatments and cures,
• sharing information,
• helping to raise awareness and
• advocating on behalf of patients and their families.

LBC does not receive government funding and relies entirely on the generous support of individuals, companies, trusts and grants, and fundraising events.

No person should rely solely on the contents of this publication without first obtaining advice from their treatment specialist.

Do you have a comment about this edition of Myeloma Today? We are always open to suggestions about this newsletter and welcome contributions.

Georgie Hackett, Editor
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Email georgie@leukaemia.org.nz

If you would like to share your story, please contact your local Support Services Coordinator on 0800 15 10 15.

leukaemia.org.nz