MDS news.

For people with MDS & their families

Leukaemia Foundation
VISION TO CURE
MISSION TO CARE

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Bill Stinson and Genie Wilson travel at every opportunity and have been overseas six times since Bill's diagnosis five years ago.

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Bill is 'a six-week man' on azacitidine

Bill Stinson who was diagnosed with MDS in early-2012 – just months after his retirement and a year after having kidney cancer, has completed his 31st cycle of azacitidine.

"I've had a few ups and downs with my blood counts, but otherwise I'm travelling okay," said Bill, 64, of Sydney.

His white blood cell count (WBC), which had been low in late-2010, recovered after surgery to remove his left kidney. However, towards the end of 2011, his WBC started going down again, and in February 2012 Bill was referred to a haematologist and a bone marrow biopsy revealed he had MDS.

"I didn't know what MDS was, even though I read very widely and have long had a subscription to *New Scientist*," said Bill.

"MDS was explained to me briefly and I was told my long-term prognosis was unknown. It could continue as is or worsen, and as worst scenario – the MDS could turn into AML. A drug was available to manage MDS and it may or may not work for me. But at that stage, because of my blood counts, I wasn't eligible for it under the Pharmaceutical Benefits Scheme (PBS), so I would be monitored with regular blood tests.

"... after my first cycle of azacitidine I had improved, and my blood counts were all back to normal after the third cycle, ..."

"I went home and Googled MDS, quickly found the Leukaemia Foundation's web page and requested copies of the MDS, eating well, and living with blood cancer information booklets. They were very informative and I didn't look at much else as I don't believe in Googling for medical information," explained Bill, a retired university librarian.

"I was on wait and see, with blood tests every six weeks.

"My blood results didn't meet the requirements for azacitidine (Vidaza®) under the PBS, but my haemoglobin was low so I felt tired and my immunity was low."

Bill had a second biopsy, in September 2012, but still didn't qualify to begin treatment, so he and his partner of 30 years, Genie Wilson, took the opportunity to make a short trip to New Zealand.

By early-2013, he had become dependent on blood transfusions, his blood counts were "going southwards", and he felt puffed walking to the shops.

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World-first liquid biopsy for MDS

People with MDS and other blood cancers could soon have access to a simple blood test to monitor their disease.

How the innovative new test can be applied in clinical cases of MDS was published in two leading journals, *Nature Communications* and *Blood*, in March.

The world-first liquid biopsy for blood cancers was developed at the Peter MacCallum Cancer Centre (Melbourne) by Associate Professor Sarah-Jane Dawson and Professor Mark Dawson, with funding support from the Leukaemia Foundation.

It promises a new era of less invasive, more precise, and effective management of blood cancers including MDS, in place of painful bone marrow biopsies.

The test monitors tiny fragments of DNA that cancer cells emit into the blood stream, called circulating tumour DNA (ctDNA). Unlike traditional biopsies, ctDNA tests track disease status throughout the body, can be used at any time over the course of treatment, and enables rapid adjustments if a person with MDS relapses or fails to respond to therapy.

Associate Professor Sarah-Jane said this ctDNA test will also help to more rapidly advance the availability of new precision medicines and targeted therapies as these are developed.

"Not only does this new test promise clinicians and patients a more timely and accurate understanding of whether a cancer treatment is working, it gives scientists the ability to quickly and effectively evaluate how clinical trial patients are responding to new life-saving therapies," said Assoc. Prof. Dawson.

The liquid biopsy also addresses a major limitation in the current approach to managing blood cancers according to Professor Mark Dawson.

"We know that a single tissue biopsy from the bone marrow or lymph node does not accurately reflect the composition of the whole tumour," he said.

"Because cancer cells from all disease sites within the body shed their DNA into the bloodstream, we found that ctDNA collected from a routine blood sample more accurately mirrors the disease across all parts of the body.

Professor Mark Dawson.

"This ctDNA test for blood cancer therefore provides a much more comprehensive picture of how a patient is responding to their treatment," Professor Dawson said.

Professor Mark Dawson has a Leukaemia Foundation Senior Research Fellowship of $200,000 per year from 2013-2017.

Blood Buddies has connected 200+ people with blood cancer

There is a high level of interest in our Blood Buddies program which has matched more than 250 people with a blood cancer or blood disorder to a trained 'Buddy'.

National Blood Buddies Coordinator, Chloe Nunn.

The Leukaemia Foundation's National Blood Buddies Coordinator, Chloe Nunn, said the phone-based peer support program has received outstanding support from people keen to share their blood cancer experience with others.

Blood Buddies matches and connects people newly diagnosed with blood cancer with volunteers who have had one of the blood cancers themselves.

"Talking to someone who has been there and done that can help you feel less alone and more able to manage your health," said Chloe.

"Having a Buddy can be particularly powerful in reducing the sense of isolation and in providing reassurance and support.

"So far, of the 178 qualified Buddies across most of the blood cancers and disorders, six have an MDS diagnosis and there have been 14 matches between those more recently diagnosed with MDS and others further down the track.

"We really need to recruit and train more Buddies who are living with this rare blood cancer, so we can offer this important support service to more people.

"If you feel you can offer short-term one-on-one support to someone else at an earlier stage of this disease experience than you, please let us know you're interested in the program," Chloe said.

For more information and to register your interest in becoming a Blood Buddy or being matched with a Buddy, call 1800 007 343 or email: **bloodbuddies@leukaemia.org.au**.

MDS information in Maltese, Dutch, Spanish & 101 other languages

While the Leukaemia Foundation's website (www.leukaemia.org.au) has extensive information on MDS, information on this rare blood cancer is available in a range of languages from the U.S-based MDS Foundation.

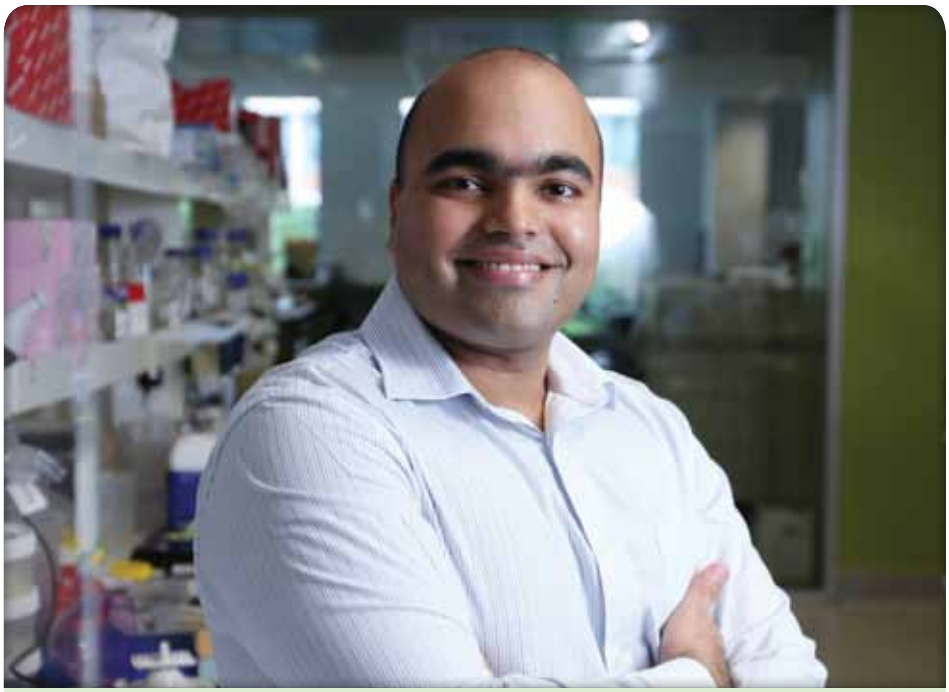
If you go to their website at: **www.mds-foundation.org** you have the choice of reading the entire website in more than 104 different languages, from Afrikaans to Zulu, and this includes the webpage dedicated to 'Understanding MDS'.

To select or change the language choice at any time, go to the language box featured in the menu at the top of each page of the website.

The bone marrow of people with MDS cannot produce enough healthy blood cells, which is explained in the information booklet, *What Does My Bone Marrow Do?* is available in 11 languages and each version can be downloaded from the site: **https://www.mds-foundation.org/bone-marrow-handbook/#International-Handbooks**

Test to predict response to azacitidine treatment in high-risk MDS

Development of a new test is well underway to identify those people with high-risk MDS who will respond and those who won't respond to standard of care treatment – azacitidine (Vidaza®).



Dr Ashwin Unnikrishnan says Australia is doing "top notch MDS research".

Research fellow, Dr Ashwin Unnikrishnan, said an integral part of this project was also to find an effective alternative treatment for MDS.

The Leukaemia Foundation provided vital early funding* for the biological work that set the groundwork for the test that could become the world's first prognostic tool to predict azacitidine response or resistance early in the treatment of high-risk MDS.

Dr Unnikrishnan, who gained his PhD studying epigenetics and how it controls biological processes, came to Australia from the Fred Hutchinson Cancer Research Center in the U.S. in 2011 to lead this research. He was recruited to work alongside fellow chief investigator, Professor John Pimanda, at the Lowy Cancer Research Centre at the University of New South Wales.

"My expertise in epigenetics and molecular biology equipped me well to understand the processes that go awry in MDS and CMML, including tackling the mystery of how 5-azacitidine therapy works or, equally importantly, why it doesn't work," said Dr Unnikrishnan.

"Coming into this field from a different background unencumbered me from having to follow the traditional thinking of haematological research, allowing me to view the problem and to find appropriate solutions from a different angle."

The primary disease modifying treatment for high-risk MDS is azacitidine – an epigenetic modifying drug PBS-listed for the treatment of high-risk MDS and CMML since 2011.

Dr Unnikrishnan said half of all high-risk patients treated with azacitidine respond to this treatment, showing an improvement in their blood counts and having a reduced risk of transforming to acute myeloid leukaemia.

"Unfortunately azacitidine is not a cure and three big questions have framed this research work right from the beginning," he said.

"These are based around why approximately half of those treated with azacitidine never get a response, and why a significant number of the people who do respond will relapse within a two-year period.

"And the sad part is that the prognosis for those who initially fail to respond at all to azacitidine therapy, and those who initially respond and then relapse, is very poor, and there is no other alternative treatment for them.

"There also is no way of predicting early whether someone will respond to azacitidine, or not.

"When a patient is given the treatment, it's wait and watch, because it takes up to six months for a response, and if they don't respond, there's basically nothing more we can do for them," said Dr Unnikrishnan.

"We thought this situation wasn't good enough and we should do something about it.

"So another question was – can we identify people upfront, early on, before the six months, and can we do something for them?"

A small-scale investigator-driven clinical trial was opened in Australia in 2008 that recruited people with high-risk MDS and CMML, from NSW and the ACT, who were given compassionate access to azacitidine.

Bone marrow samples were collected before treatment started, with additional biopsies taken regularly during the six months the trial participants received azacitidine.

By the end of the trial, in 2011, bone marrow samples had been collected from 21 patients – half with MDS and half with CMML.

"Our discoveries wouldn't have been possible without the support of these patients and their contributions will help future patients," said Dr Unnikrishnan.

"From the samples, we isolated the haematopoietic stem and progenitor cells (HSPCs) as we believe MDS and CMML arise from problems with the HSPCs.

"Using a new technology, called high-throughput sequencing, we could look at the expression of all the genes in a cell at the same time and identify which were turned 'on' or 'off'," Dr Unnikrishnan explained.

"We used this information and the hypothesis we were testing (about who did and didn't respond) to see if there was something that explained the difference."

The analysis was carried out retrospectively, using the sample collections, and knowing which samples were from responders and non-responders.

"There were fundamental molecular differences, so we went on to validate these differences, through collaborations in the UK and Sweden. We wanted to ensure our findings weren't parochial and that they occurred more generally, in larger numbers of patients from across the world, which they did.

"We thought this situation wasn't good enough and we should do something about it."

"We found the cells of patients who responded to azacitidine went through the cell cycle more efficiently; their cells were dividing and active. The non-responders' cells were quiescent – they were quiet and not doing much, and fewer cells were going through the cell cycle.

"We identified the cell cycle quiescence as a predictive quality, which we then validated.

Continued on page 5.

Continued: Bill is 'a six-week man' on azacitidine

"If there are sudden changes in temperature, I am in danger of getting a cold which for me can turn into an upper respiratory tract infection," said Bill, who grew up on a wheat and sheep farm and can also suffer from hay fever and allergies.

"I'm very careful to keep my body at an even temperature and to carry a jumper and jacket with me."

Bill found out he was eligible for azacitidine after his third bone marrow biopsy, in April 2013. But he was admitted to hospital with a temperature and needed intravenous antibiotics as well as blood and platelet infusions before he could start his first cycle of chemo injections.

"I was told I'd have to wait four to six months to see changes from the treatment, but after my first cycle of azacitidine I had improved, and my blood counts were all back to normal after the third cycle," said Bill.

He has continued this treatment since then and when he spoke to *MDS News* he was having his 31st cycle. He hasn't needed to be transfused and says his only problem is the chemical burn he gets on his stomach.

"My skin comes up red and sore from the 14 injections I get over seven days. I like to put on moisturising cream and always have a cold pack with me, and I have the injections late in the afternoon so I can get in and out of hospital fairly quickly."

"... I was 'a six-week man' and I couldn't have had a better Christmas present ..."

Bill and Genie love travelling and, in August 2013, the day after completing his treatment, they flew to New York and visited family in Canada.

"I was sore on the outgoing flight but, as a friend said, I may as well be sore on a plane going somewhere than sitting at home!"

In 2014, Bill started feeling nauseous at the beginning of his injections and was put on anti-nausea medication, which in turn led to constipation.

"I am a keen cook and to help myself in this regard, during the week of my injections, I eat meals which will not cause me problems such as pasta (with lots of oil and vegetables and only a little meat) laksa, rice dishes, bean dishes, and quiches."

Bill and Genie travelled again in mid-2014, visiting friends in the U.S., but the next trip they had planned, to Italy in September that year, had to be cancelled.

"My white cells were not high enough to start the chemo, so that cycle was delayed a week, and I lost money on the airfare as MDS is not covered by my travel insurance.

"A couple of weeks later, we went to Western Australia for three weeks instead, and after that, I decided to book all future trips only after getting my blood test results," he said.

Until then, Bill's four-week azacitidine protocol had gone well, but during 2015 he increasingly "had troubles" with his WBC not recovering sufficiently after each treatment.

"This meant I had very low or no immunity. I had to progressively extend the time between starting the next cycle by a week or two, and in December 2015 my haematologist agreed to my cycles being extended to every six weeks," said Bill.

"My haematologist said I was 'a six-week man' and I couldn't have had a better Christmas present; not as many injections, not as many sore stomachs and best of all – a 30-day break to go on a holiday if I wished," said Bill, who hasn't had any further problems with his counts.

"Every time I have a blood test, they're perfectly normal".

After two years on azacitidine, Bill had his fourth bone marrow biopsy, in April 2015, to gauge his treatment response.

"As I felt okay, I wasn't worried. While waiting for the results, we traded in our old car, purchased a Subaru Forrester and drove to the Sturt National Park.

"We enjoy driving trips, looking at natural sights and taking photos.

"I don't believe in worrying or thinking about some things until I need to and I have the necessary information."..."

"The results showed no change from the biopsy in April 2013, so that was good news.

"I was given a six-week break, so we packed the car and went on a road trip to South Australia, Central Australia, the Northern Territory and home via south-east Queensland. It was a great trip and very refreshing."

Since having MDS, Bill has continued with his various "research projects" which are based on his love of history, mapping, and editing and restoring family films and photographs.

When Bill was given a six-week break from treatment, he and Genie packed their car and went on a road trip.

And despite not having MDS included in his travel medical insurance, he and Genie have travelled often and have been overseas six times since his diagnosis.

"I travel the day after my last injection, which used to give me 19 days away. Now with a six-week cycle, I get 31 days. I fly out on a Thursday, go where we want and get back the day before my next blood test," he explained.

"I may have been told what type of MDS I have. If so, I can't remember and at this stage I'm not really interested in knowing.

"If something starts going wrong then I will find out more from my haematologist. I don't believe in worrying or thinking about some things until I need to and have the necessary information.

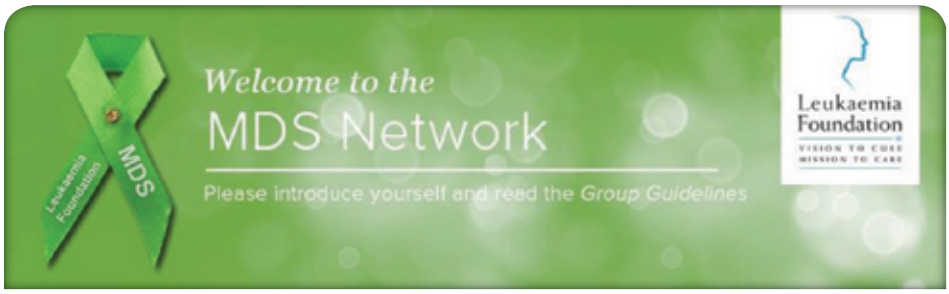
"While all is going well I want to enjoy life as much as I can and finally do the things I have talked about for some years. So far I have been very fortunate.

"I'm grateful for the treatment and care I am receiving. I enjoy attending the talks arranged by the Leukaemia Foundation because I find the information about new research and developments interesting, and the posts on the MDS Network Facebook page.

"What I do need to do is a little more exercise!"

MDS Network Facebook group growing

It's 18 months since the Leukaemia Foundation launched the MDS Network on Facebook, which now has 108 members and membership is steadily growing.



This closed 'members only' group was established to provide a private, friendly and supportive place where people from around Australia can connect with others affected by MDS, to share their personal experiences. In this online space, the opinions of others are valued and members are accepted for who they are.

The Foundation's General Manager, Research, Advocacy & Services, Caroline Turnour, said the empathy and support members provide to each other through this forum has exceeded expectations for the group.

A typical post along that vein: *"I wish you the best of luck with your MDS journey. Enjoy the good days as they come, try to keep positive, stay fit, eat well and surround yourself with loving and positive people. I think that's why I am still ok after so many years".*

Many members tell their individual stories of diagnosis: *"I am new to the group but not to MDS, having been diagnosed with what is now described as the RCMDRS version 12.5 years ago and have been having blood transfusions for 12 years now".*

What's happening to them in real time: *"Well we are about to start the next part of this adventure. 6th cycle of azacitidine".*

And most are philosophical about their future: *"I don't dwell on the diagnosis, just make the most and be thankful".*

The range of topics discussed within this network is widespread. Aspects of the MDS journey are described, often in detail, such as the experience of having a bone marrow transplant, which is gratefully received: *"When faced with the prospect of a SCT it's encouraging to hear of other's successful journeys".*

Questions are asked about practical issues, such as feedback about side-effects, ideas about what might be causing heart palpitations, and whether anyone from the group has taken deferasirox.

Members check in regularly with each other: *"How are you travelling. Have you had your SCT yet, or is it scheduled?".*

And a recurring theme is appreciation of the group: *"In lieu of miracles, there's lots of advice/support on this web site! I wish you well".*

People share links to relevant scientific articles, those with an analytical bent want details such as members' blood types, and a discussion thread links to a survey that measures how one is feeling and tracks symptoms and side-effects.

Leukaemia Foundation blood cancer support coordinators moderate the network and ensure adherence to the Group Guidelines, so it remains safe and positive, and where members lead the discussion.

For those who choose to watch from the sidelines, members are welcome to learn, discover and read what they feel is relevant to them, with no expectation to post or share in the discussion.

Those new to Facebook are encouraged to dip their toes in the water, as this connection with others in similar circumstances can be reassuring.

To join, go direct to: **https://www.facebook.com/groups/MDSAus/**

Continued: Test to predict response to azacitidine treatment in high-risk MDS

"We used flow cytometry – a technique that uses a machine commonly available in hospitals – to look at the proteins produced by the genes. Again we identified, with high accuracy, markers of cell cycle quiescence that identified the responders and non-responders.

"Our work has always had a very translational focus, and our final goal is to move this predictive test into the clinic, to determine whether there is a high chance you are likely to respond or a high chance you will be a non-responder.

"We need to validate this prognostic tool in large numbers of patients and to define the boundaries of the response," said Dr Unnikrishnan about a new clinical trial that was being planned along with a proposal for funding.

"We hope this test will be a diagnostic assay, which doesn't exist anywhere in the world at the moment," Dr Unnikrishnan said.

"Then what we want to do is provide an alternative treatment, to improve the response rates, and to give clinicians more tools in their arsenal to treat patients.

"Based on our molecular understanding of why patients don't respond (to azacitidine), we've identified a pathway, integrin alpha5, which leads to cell cycle quiescence in the non-responders.

"By blocking the signalling, through integrin alpha5, the cells are more responsive to azacitidine treatment.

"However, azacitidine is not eradicating the MDS cells that are persisting in the blood. This means the fundamental characteristics of MDS are still there, we haven't got rid of the problem and it's a ticking time bomb.

"We need a better treatment that targets those cells and eradicates them at a molecular level, for a more durable cure.

"We don't know what we'll find but we know what we need to do.

"We are delighted at how on board patients are at wanting to help us out with research. They are keen to know how things are going and what we're discovering, and our findings would not have been possible without them."

"Funding* from the Leukaemia Foundation was essential in establishing the initial trial that resulted in the valuable samples being banked.

"Discoveries take time and later additional funding from the Foundation was important to keeping things going.

Dr Unnikrishnan said Australia was doing "top notch MDS research".

"Our MDS bone marrow sample collection is unmatched and enduring.

"It took a lot of upfront planning and was labour intensive, but helped set the platform for the work that has happened and future work. They are still banked and open up new areas of research for our future work and new trials will provide access to more samples," he said.

** Dr John Pimanda received a Leukaemia Foundation Career Establishment Grant of $50,000 per year from 2009-2011 (Identifying genes that are abnormally switched off in myelodysplasia), and in 2013, Dr Ashwin Unnikrishnan and Dr John Pimanda were awarded a Grant in Aid of $100,000 in 2013: (Identifying the differences between cancer stem cells and normal stem cells). They were invited to present their findings at the American Society of Hematology (ASH) annual conferences in 2015 and 2016, and at the European Hematology Association Congress in 2016.*

MDS research update from ASH 2016 Annual Meeting

By Dr Mikkael Sekeres Director, Leukaemia Program,*
Department of Hematologic Oncology and Blood Disorders
Cleveland Clinic Taussig Cancer Institute (Ohio, U.S.)

Research studies that directly affect people with MDS were presented at the American Society of Hematology Annual Meeting last December – the world's largest professional gathering of haematologists and haematological oncologists.

This conference is where many major findings in the field of blood and bone marrow disorders are first announced to attendees – the larger medical and scientific community.

New therapies

There has been some advancement in the area of new therapies for MDS and an exciting drug approach was a presentation about enasidenib – an IDH2 inhibitor. About 5-10% of MDS patients have a genetic abnormality that caused their MDS (not one that's passed down to their kids or grandkids). This drug targets and fixes that abnormality, at least temporarily. Patients who'd had a variety of other drugs got better and some then underwent a BMT.

Another drug approach is a drug that's very similar to azacitidine (Vidaza®) and decitabine (Dacogen®). It's another hypomethylating agent that seems to work as well as these other two drugs but will represent an alternative in the future.

There were presentations on early results of studies on drugs that 'harness the immune system' to attack cancer or MDS. They don't appear to be working as well as we'd like as individual drugs, but there were some very interesting data about patients who got better when one of these drugs was combined with azacitidine.

A lot of data looked at the genetics of MDS. If we are able to understand this constellation of disorders better, we're going to be able to better treat it in the future.

Combination therapies

A couple of studies combined drugs that are already available, to see whether they work better together than they might individually. One, from Europe, combined lenalidomide (Revlimid®) with an epoetin alfa (EA) stimulating agent, either erythropoietin or darbopoietin. Another, from the U.S. asked essentially similar questions. The results of these studies are a little bit contradictory. The European study seemed to indicate no advantage to adding an EA to lenalidomide in patients who don't have the deletion 5Q abnormality. On the other hand, the U.S. study showed that there was some advantage to adding two drugs together. We'll have to wait and see how the results mature over time and hopefully we will find some combined data to come up with an answer to whether two drugs are better than one.

Bone marrow transplants

We consider bone marrow transplants (BMT) for patients with higher-risk MDS at diagnosis. Some people want to go through this high-risk procedure and some people don't, but BMT does represent the only cure for MDS. One of the largest studies presented this year looked at the genetics (of what's caused the MDS) of patients with MDS and looked at how patients did going through a BMT. This identified a couple of abnormalities where, unfortunately, people did poorly going through a BMT. We're getting better at identifying groups of patients who could benefit from a transplant and thinking about different treatment options for those patients who can't benefit from a BMT.

Precision medicine for MDS

Precision medicine – another catchphrase you hear a lot about – means identifying specific abnormalities within MDS that we can target with a drug, so really take care of MDS at its core. We're getting much better at that by identifying the causes of these diseases. We can identify specific genetic abnormalities in more than 90% of people with MDS. The IDH inhibitor mentioned earlier is a precision medicine initiative – it's targeting these abnormalities. There are drugs referred to as FLT3 inhibitors. Some patients with MDS, particularly as their MDS gets worse, can develop these genetic abnormalities. A clinical trial, conducted through the MDS Clinical Research Consortium, looked at the value of monitoring patients over time for these genetic abnormalities and found a certain subset of patients did develop genetic abnormalities for which we have specific drugs. There's more to come in this area, as we increasingly recognise drugs that target patients with very specific precise genetic abnormalities.

To find out what MDS therapies or clinical trials are available to you, ask your haematologist or specialist, and download the ClinTrial Refer ANZ app which lists active and pending haematology clinical research trials in Australia and New Zealand, or **clinicaltrials.gov**

Dr Mikkael Sekeres.

Advance Care Directives – what are they and do you need one?

People with MDS, along with all people in the community, should consider having an Advance Care Directive (ACD).

Individuals are becoming more familiar with this written legal document in which a person makes their wishes known regarding their future end-of-life healthcare.

Many of us have an idea of what we may or may not want to happen if a catastrophic health event occurs – a car accident, a stroke – or progression of a terminal disease. In such circumstances, you may no longer be competent to make informed decisions regarding your own healthcare.

As this could happen to any of us, at any time, the time to make your ACD is when you are well.

An ACD extends the current right of a competent person to refuse treatment to a future time when they may not be competent.

Due to better living conditions and health care, we are living longer. And rapid technological developments means people who would previously have died can be kept alive for long periods of time, often through the use of ventilators (assisted breathing) and PEG tubes (feeding via a stomach tube). This has led to practical, legal, and ethical issues regarding end-of-life care and extending the dying process, which poses the question – are we prolonging life or extending dying?

What the law allows

Both common law and statute law in Australia supports the right of a competent person to withhold consent or refuse medical or other treatment, even if this results in that person's death. The rights of a non-competent person who has expressed their wishes in an ACAD, will be followed.

Your treating doctor will consider your ACD valid if:

- you had full decision-making capacity when you wrote it;
- it specifies details about treatments you would accept or refuse;
- it is current (i.e., not written a long time ago and you have not changed your mind since writing it); and
- you were not influenced or pressured by anyone else when you wrote it.

Note: an ACD is not a form of euthanasia as it allows only those actions a person would legally consent to if they could speak and give competent direction to medical personnel themself. Also, an ACD comes into effect only when the person who made it loses their decision-making capacity.

The right to refuse treatment – can you do that?

Every competent person is entitled to refuse treatment. It is a legal and moral right, under both common law and (in some states/territories) statute law relating to assault.

Here are some major benefits of ACDs:

- Gives clear healthcare direction to healthcare providers.
- The patient has control, even when they are no longer competent, which ensures their wishes for end-of-life health-care are known.
- Relieves stress for family members who are trying to make difficult decisions at a traumatic time.
- Gives a well person security regarding future health events, thus enabling them to live well now by taking away fear about their end stage of life.

Advance care planning supports better decision-making at end-of-life for patients, their carers and health professionals. Initiating conversations about this topic can be challenging and there are several key legal concepts that are important to be across.

Legal advice is not necessary to write an ACD although it is advisable if you are unsure. There are websites that are dedicated to ACDs and where you can download and print your own.

This useful link to Advance Care Planning Australia has additional links for each state and territory, including printable documents.

http://advancecareplanning.org.au/advance-care-planning/

Here is the "extremely positive" personal experience of a Leukaemia Foundation Blood Cancer Support Coordinator whose loved one had an Advance Care Directive.

"My dear mum made her ACD about 15 years before her death, when she was in very good health. She had strong beliefs about what she did and did not want if she became gravely ill, and she updated the signatures approximately every year.

"No one knows if they will need an ACD but in this case we did. I didn't have to make those really difficult decisions, as they were all there in black and white. That was a blessing and a huge relief."

NEW SOUTH WALES		
Sydney Metro		
15 May	10am-12pm	Liverpool Blood Cancer Education & Support Group (also 19 Jun, 17 Jul, 21 Aug, 18 Sep, 16 Oct, 20 Nov)
17 May	2-4pm	Randwick Blood Cancer Education & Support Group (also 21 Jun, 19 Jul, 16 Aug, 20 Sep, 18 Oct, 15 Nov, 13 Dec)
29 May	10-11.30am	St George Blood Cancer Education & Support Group (also 26 Jun, 31 Jul, 28 Aug, 25 Sep, 30 Oct, 27 Nov)
31 May	11am-1pm	Westmead Blood Cancer Education & Support Group (also 28 Jun, 26 Jul, 30 Aug, 27 Sep, 25 Oct, 29 Nov)
1 Jun	2-4pm	Penrith Blood Cancer Education & Support Program
28 Jul	10am-12pm	North Sydney Blood Cancer Education & Support Group (also 25 Aug, 29 Sep, 24 Nov)
11 Aug	10am-12pm	Concord Blood Cancer Education & Support Group (also 8 Sep, 13 Oct, 10 Nov, 8 Dec)
Central Coast		
25 May	10-11.30am	Gosford Blood Cancer Education & Support Group (also 29 Jun, 27 Jul, 31 Aug, 28 Sep, 26 Oct, 30 Nov)
30 May	2-3.30pm	Wyong Blood Cancer Education & Support Group (also 27 Jun, 25 Jul, 29 Aug, 26 Sep, 31 Oct, 28 Nov)
Central West & Far West		
1 Jun	10-11.30am	Orange Blood Cancer Education & Support Group
7 Jun	10.30am-12pm	Dubbo Blood Cancer Education & Support Group
8 Jun	11am-12pm	Mudgee Blood Cancer Education & Support Group
Hunter		
6 Jun	10am-12pm	Newcastle Blood Cancer Education & Support, Mayfield (also 8 Aug, 10 Oct, 12 Dec)
13 Jun	10-11.30am	Port Stephens Blood Cancer Education & Support (also 11 Jul, 15 Aug, 12 Sep, 21 Nov)
4 Jul	10am-12pm	Newcastle Blood Cancer Education & Support, Shortland (also 15 Sep, 14 Nov)
Illawarra & Shoalhaven		
24 May	10am-12pm	Bowral Blood Cancer & Support Program (also 26 Jul, 27 Sep, 22 Nov)
7 Jun	10.30am-12.30pm	Wollongong Blood Cancer Education & Support Group, Figtree (also 5 Jul, 2 Aug, 6 Sep, 4 Oct, 1 Nov, 6 Dec)
Mid North Coast		
15 May	10-11.30am	Port Macquarie Blood Cancer Information & Support Group (also 19 Jun, 17 Jul, 21 Aug, 18 Sep, 16 Oct, 20 Nov, 18 Dec)
25 May	11.30am-1pm	Coffs Harbour Blood Cancer Information & Support Group (also 22 Jun, 27 Jul, 24 Aug, 28 Sep, 26 Oct, 23 Nov)
New England		
16 May	1.30-3pm	Tamworth Blood Cancer Information & Support Group (also 20 Jun, 18 Jul, 15 Aug, 19 Sep, 17 Oct, 21 Nov, 19 Dec)
13 Jun	2-3.30pm	Armidale Blood Cancer Information & Support (also 11 Jul, 8 Aug, 12 Sep, 10 Oct, 14 Nov, 11 Dec)
Northern Rivers		
21 Jun	10am-12pm	Tweed Blood Cancer Education & Support Group
22 Jun	10am-12pm	Grafton Blood Cancer Education & Support Group
NORTHERN TERRITORY		
25 May	10-11.30am	Alice Springs Blood Cancer Support Group (also 29 Jun, 27 Jul, 31 Aug, 28 Sep, 26 Oct, 30 Nov)
31 May	6-8pm	Men's Shed, Darwin (men only support group) (also 28 Jun, 26 Jul, 30 Aug, 27 Sep, 25 Oct, 29 Nov)
5 Jun	6-8pm	Women's Group, Darwin (also 3 Jul, 8 Aug, 4 Sep, 2 Oct, 6 Nov, 4 Dec)

QUEENSLAND		
17 May	10am-12pm	Blood Cancer Information session, Cairns
17 May	11am-1pm	Brisbane Coffee Cake & Chat (also 10am-12pm 17 Aug, 16 Nov)
27 May	9am-3pm	Bouncing Back: using the diagnosis to transform your life, Brisbane (also 3 Jun)
30 May	10am-12pm	Charters Towers Coffee Cake & Chat
31 May	10am-12pm	Gold Coast Coffee Cake & Chat (also 8 Jun, 23 Aug, 22 Nov)
8 Jun	10am-12pm	Ingham Coffee Cake & Chat
13 Jun	10am-12pm	Mackay Coffee Cake & Chat
22 Jun	10am-12pm	Toowoomba Coffee Cake & Chat (also 14 Sep, 7 Dec)
24 Jun	12-2pm	20/30 Chat, Brisbane
14 Jul	10.30am	Sunshine Coast Post BMT Coffee Cake & Chat
27 Jul	10am-12pm	Atherton Patient Information Seminar (also 30 Nov)
19 Oct	10am-12pm	Innisfail Coffee Cake & Chat
SOUTH AUSTRALIA		
Adelaide Metro		
6 Jun	10am-12pm	Women's Group, Adelaide (also 4 Jul, 1 Aug, 5 Sep, 3 Oct, 7 Nov)
8 Jun	10am-12pm	Southern Adelaide Support Group (also 13 Jul, 10 Aug, 14 Sep, 12 Oct, 9 Nov)
14 Jun	10am-12pm	Amyloidosis/MDS/MPN and WM Support Group, Northfield (also 9 Aug, 11 Oct)
20 Jun	10am-12pm	Northern Adelaide Support Group (also 15 Aug, 17 Oct)
21 Jun	10.30am-12.30pm	Strathalbyn Support Group (also 19 Jul, 16 Aug, 20 Sep, 18 Oct, 15 Nov)
27 Jun	10.30am-12.30pm	Men's Group, Adelaide (also 29 Aug, 31 Oct, 19 Dec)
Regional South Australia		
24 May	5.30-6.30pm	Mount Gambier Support Group (also 5 Jul, 6 Sep, 1 Nov)
13 Jun	10am-12pm	Port Lincoln Support Group (also 8 Aug, 10 Oct)
TASMANIA		
Northern Tasmania		
16 May	10.30-11.30am	Caring for the Carer, Devonport
11 Jul	9.30am-12pm	Cooking for Chemo, Launceston
VICTORIA		
Metro Melbourne		
25 May	10-11.30am	Eastern Melbourne Blood Cancer Support Group
8 Jun	10-11.30am	Melbourne Man Cave
Grampians		
5 Jun	9.30-11am	Ballarat Blood Cancer Support Group
Hume		
7 Jun	10-11.30am	Echuca Blood Cancer Support Group
Loddon/Mallee		
5 Jun	9.30-11am	Bendigo Blood Cancer Support Group
19 Jun	1.30-3.30pm	Mildura Blood Cancer Support Group

NATIONAL TELEPHONE FORUMS

Telephone forums are held regularly for patients in regional and remote areas, and metropolitan patients who have difficulty accessing our support and education activities. Men's Telephone Forum: 19 July, 20 Sep & 15 Nov, 2-3pm. To register or to find out more, contact Andrew Read on 0439 500 951 or aread@leukaemia.org.au

NATIONAL MDS DAY – JULY 14

Leukaemia Foundation
VISION TO CURE
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Join the MDS Network closed group on Facebook: www.facebook.com/groups/MDSAus/
Visit www.leukaemia.org.au for our latest Education and Support Program Event Calendar.
To register for an education or support event, freecall 1800 620 420 or email info@leukaemia.org.au

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