Polio NZ Inc

POLIO NEWS

December 2016

Wishing Everyone a Joyful Festive Season and a Happy And Prosperous New Year!

Lisa Jarmaat and Marlayna Zucchiatti got an early start to their celebrations at the Polio NZ Retreat in August. They were mugging for the camera of Vice-president, Sue Griffin, one of the Retreat's guiding lights. More of Sue's photographs are featured inside. Also, don't miss President Barry Holland's summary of the year.

PolioNZ Inc.

Polio NZ is an incorporated society dedicated to seeking support for people who have had poliomyelitis. It does this through information sharing and where possible, assistance to Polio NZ Inc. members and their families, whether or not they are experiencing problems at present.

The Society's Board of Management meets monthly by teleconference, and the Annual General Meeting is held in October.

Polio News is published three times a year in April, August and December and sent to all members.

Contributions are welcomed and the deadline for copy is the 5th of the month prior to publication. Ideally, it should be received well before that date.

Disclaimers: Opinions expressed in Polio News are those of the writers and not necessarily those of the Society.

This newsletter is not intended to provide medical advice. For decisions about health matters, first consult your health professional.

Similarly, no brand name product mentioned in this newsletter has any formal endorsement by Polio NZ.

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The Society expresses thanks to the Lottery Grants Board for its assistance towards the costs of this newsletter.

Our President says:

What a Great Year!

I'm delighted with the progress made this past year as your Board has continued to search for new initiatives to assist those of us experiencing the late effects of Polio.

It's important to acknowledge that the progress is due in large part to former Board member Gordon Jackman, who was chosen as Polio NZ's first Programme Manager, following the Board's establishment of the role at last year's AGM.

We were extremely fortunate to get financial backing for this initiative from our long-time partners at the Sir Thomas and Lady Duncan Trust who agreed to fund Gordon for six months. Our huge thanks to the Trust

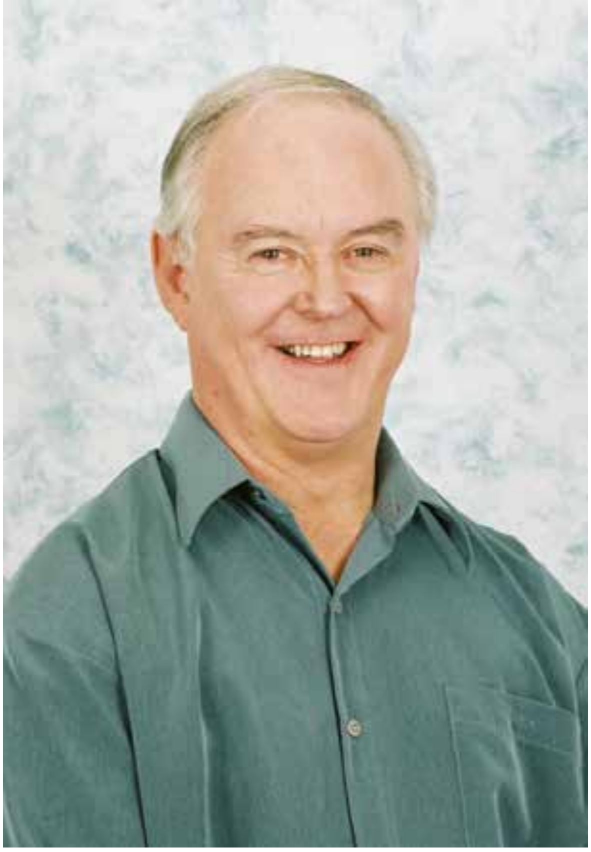
Here is a quick summary of what Gordon has been working on in the past year.

Polio Clinic/Service Facility

The main plank in our strategic plan is to have a facility available where our members can be assessed regularly and given advice on how to manage themselves and keep their independence, as we endure the late effects of Polio.

In this area Gordon's been successful in getting a neuro-physiotherapist from Auckland and a physio from Christchurch on board. Both are extremely enthusiastic in wanting to help us create the appropriate facility.

Testament to this is they've both gone out of their way in their own time to learn as much as they can about our specific situation and needs – so much so, they even went to the recent Conference in Sydney to learn about what's happening overseas.



Barry Holland

Gordon has also re-established our relationship with QE Health in Rotorua, where we held this year's retreat. QE are very keen for us to use their extensive facilities, just as some of you have done in the past.

Health Professionals.

Gordon has worked tirelessly, not only with health professionals but also the DHBs, to create a greater awareness of the Late Effects of Polio (LEOP). He's already getting clear signs of growing interest from health professionals, but the real surprise is that he's getting positive signs from the DHBs as well. Wow ... wouldn't that be a breakthrough if we could get the public health system on board! Well, Gordon's making it look more and more likely.

(Continued over)

(President's Report Continued)

Orthotics

Orthotics is a particular area of concern for a lot of our members, so Gordon carried out a survey this year and I say thanks to those members who gave us their thoughts. Suffice to say some of your comments ruffled a few feathers. However it didn't deter around 20 orthotists and prosthetists attending a Polio NZ workshop at QE Health in September which featured renowned American orthotist Marmaduke Loke and his dynamic bracing solutions.

This workshop not only revealed some of the advances in bracing, but was also an opportunity for our New Zealand orthotists to be up-skilled in the creation, learning and application of Marmaduke Loke's bracing techniques.

Will Gordon be able to continue in his role? The answer is YES. The Sir Thomas and Lady Duncan Trust has offered to fund him for another 12 months, for which we will be eternally grateful and indeed relieved, considering the momentum created so far with our strategic plan.

Retreat

I'd also like to acknowledge and offer thanks in this report to your vice-president Sue Griffin and her voluntary helpers, Marie Collins, Nyree Ambridge and Gina Allan-Evans, who organised another successful retreat at QE Health in Rotorua.

This is an important opportunity for our members to get together to not only listen to an inspiring group of guest speakers, but also to share their own experiences in managing LEOP.

Funding

This was an exciting aspect of the past year. Exploring extra funding avenues is vitally important for Polio NZ if we are going to continue finding ways of making our lives more comfortable.

To the fore again has been the Sir Thomas and Lady Duncan Trust to whom we continue to be eternally grateful. As well as one-off grants during the year from the Trust, we also have the Duncan Fund, a sizeable amount of money which is set aside to assist in keeping members comfortable and as mobile as possible in their homes. A huge thank you again to the Trust for their support.

The Board would also like to thank the Freemasons' Foundation for sponsoring the orthotics workshop in Rotorua. This important occasion was well-received by those orthotists who were invited and strengthened our relationship with this important group of health professionals.

Also this year a special thanks to the Lotteries Commission, which funded our administration costs. They increased their donation last year and last month they upped their generosity again. For this we are most grateful.

On behalf of the Board, I would also like to thank our members for their subscriptions and extend extra thanks to those who added donations to their subs as well. If you know of any philanthropic groups or individuals who might care to donate to our organisation , please pass the information on to our Secretary, Jeannette. It doesn't have to be a large amount, as every little bit counts these days.

We continue to get little in terms of bequests, but I can tell you that our Christchurch Support Group was this year bequeathed an extremely generous $85,000 from former group member, the late Almer Slack.

Looking Ahead

We'll review our strategic plan as we go into the new year, with the main focus being on bringing to fruition our goal of establishing a polio clinic or clinics. We'll also continue to work hard on bringing the DHBs into line with funding, so we can access the public health service. As well, we plan to update our website and data base.

Finally, Some Special Mentions

To Polio NZ's Co-Patrons David and Vicky Duncan from the Sir Thomas and Lady Duncan Trust: On behalf of the Board I cannot express enough the sheer gratitude we feel for you and your family's enduring support of our organisation.

My thanks to my fellow Board members for their support this past year. To our executive team of Secretary, Jeannette Aldridge who brings invaluable knowledge to the Board; Diane Mathews who's kept the ship on an even keel; and to Vice-President Sue Griffin, our retreat organiser and coordinator of our support groups. Thanks go to former Board member Nancy Blackstock who chairs the Duncan Fund sub-committee. Thanks also for the support that I receive from the rest of our Board members, Brian Robinson from Nelson, Susan Kerr from Picton as well as Judy Lawley and Steve Griffiths from Auckland.

My best wishes for the future go to three members of this Board who retired at the AGM – Treasurer Diane Mathews, Penny Humphreys and Heather Hopson. Sincere thanks to you all for your valuable contributions.

Subsequently, we're delighted to add three new members to our Board – Carl Pascoe and Doreen McCoard from Christchurch and Brent von Sierakowski from Auckland.

In conclusion, may the coming year be an even brighter year for all our members. Rest assured your Board will be doing all it can to make it an easier one as well.

Warmest regards,

Barry Holland
President
Polio NZ Inc.

Didn't Get to Sydney?

The Polio: Life Stage Matters conference held at the Fours Seasons Hotel in Sydney, 20 – 22 September 2016 was a real success. Polio Survivors and expert presenters from 14 countries attended, including 16 from New Zealand.

If you didn't make it, all is not lost, In the next few months it is intended that videos of all the presentations will be shown on:

http://www.polioaustralia.org.au/polio-conference-life-stage matters/

Polios Are Where You Find Them

Every now and then you get a shock to discover a new Polio. For example, how many readers were aware that Lord Snowdon (Antony Armstrong-Jones) is a Polio?

His encounter with the dreaded virus came when as a rule-breaking Eton schoolboy, aged 16, he spent six months incarcerated in a Liverpool hospital (including time in an iron lung).

Biographer Anne de Courcy records this fact in her 2008 book, *Snowdon: The Biography.*

She says, "This trauma [his brush with polio] left him with a lust for experience and a fierce resolve to be self-sufficient."

Lord Snowdon, now aged 86, is described as "rather frail" and is said to use a wheelchair and sticks.

However, he is known to be an ardent campaigner for the disabled.

Anne de Courcy says, "The long-term exclusion of wheelchair users by British Rail was a particular bugbear." She describes him as a "doughty campaigner on behalf of the disabled" and says "the Disability Discrimination Act of 1995 embodied many of his hopes."

Well, I Never!

Walt Disney asked his song writers to come up with a song for the movie *Mary Poppins* that would help convince Julie Andrews to accept the role of Mary.

One of the writers' children told Disney about the polio shot they'd just received. They said it was so easy to take because the doctor put the medicine on a sugar cube and let the children take it on a spoon. So the song *A Spoonful of Sugar* was born and Julie Andrews played her Academy Award-winning role.

Remembering Ray Wilson

July 13, 1928 – September 17, 2016

Polio NZ lost one of its champions with the death of pioneer member and former President Ray Wilson in Oamaru on September 17.

During his many years of service he tried to make contact with every support group in the country and the effectiveness of his efforts was demonstrated as tributes came in from all over.

The main article on these pages has been supplied by Susan Kerr, but notes from others have been attached.

"Our organisation was represented at his Oamaru funeral by Trish Hill and Jill Steenson," said Susan.

"It was fitting that his casket was covered with spring Daffodils as Ray and his late wife Iris had always kept a wonderfully productive garden."

In a 2002 article for the New Zealand Herald, entitled *Reminders of bad old days,* Ray told some of his polio story to Eugene Bingham.

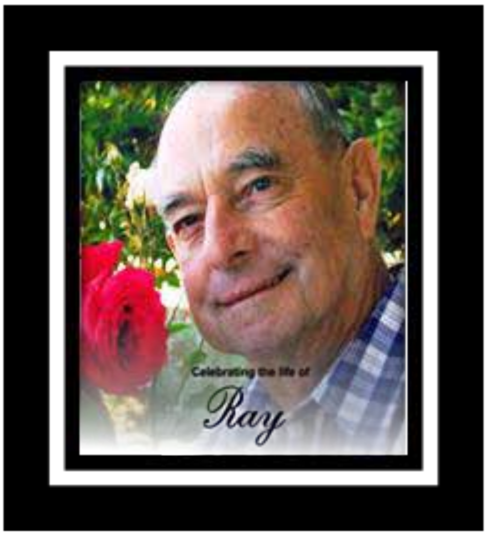
He was just eight at the time he was struck down, but he remembers the ambulance driver coming to the door on Christmas Eve, 1936, the article said.

"You'll have to carry him out," the driver told his dad. "We're not allowed to touch them."

The polio epidemic of 1936-37 was rampant, sending panic through Dunedin.

Roads north and south were closed to prevent the outbreak spreading.

As Ray lay in an isolation ward of Dunedin Hospital, listening terrified to the screams of other polio victims manacled in frames to stop their bodies from contorting, health officials turned up at his parents' house and ordered everyone out. The house was sealed up so it could be sprayed. It was a miserable Christmas Day for the Wilson family.



Ray was kept from seeing his parents and four siblings for six weeks. After four months in hospital, he was allowed to go home wearing a spinal brace that he was lumbered with for another two years. He tried to get on with life as normal but with one leg withered above the knee he could not run and would not wear shorts.

Trish Hill says that one of Ray's daughters gave the family eulogy and outlined the many interests Ray had in his lifetime and the happy family occasions.

He served his time as a carpenter although his boss at first doubted that Ray could manage the job having had Polio. "Ray managed!" His other interests were varied but his main love was the local Country Music Club of which he was a keen member, attending their many events.

It was in 1987 that Philippa Morrison became aware that Polio survivors were experiencing changes in their condition which their physicians couldn't explain when she and 13 others attended a polio conference in St Louis.

As a result of that trip, Polio survivors banded together and quietly formed support groups. The seeds of a support organisation were planted.

GPs didn't have anything to offer to the many polios presenting at their clinics so they began to share their experiences as they identified with what Americans called Post Polio Syndrome.

"Later," says Jenny Green, "we were to attend a Conference held in Christchurch where we met up with Denis Hogan, Pam Owers, Dr Liz Falkner, Lois Campbell and others. Then Richard Matches called a meeting held in the Leith Valley to assess the interest of 'local Polios' in the area and from this meeting some members of the Christchurch group and from Oamaru assisted in the setting up of the Otago Post Polio Support Group."

In 1989 a constitution was drawn up and the Post Polio Support Society of NZ was incorporated, with Philippa Morrison as the first President. In 1992 Denis Hogan became President with further developments to "the Society" during his six years of leadership.

Ray was a foundation member of the North Otago Polio support group and was the President for a time early on. This in turn led to him becoming the National President. from 1998 to 2007, and he consolidated and advanced the Society.

Ray and Dr Liz Falkner and others lobbied tirelessly for a Centre of Excellence for the treatment of PPS. They were thwarted at every turn. Medical specialists and the Government Health Department were reluctant to recognise the unique situations polio survivors faced.

Dr Liz did however negotiate with Dr Petrie to begin the two-week treatment courses for polios in 1992 at Queen Elizabeth Hospital (later QE Health).

In 2004, Ray was awarded the QSM for his services to the community. According to Jenny, Ray was involved in countless activities. He was superbly organised and kept meticulous records.

Trish comments, "When Ray was President I saw first-hand how much effort he put in."

Ray and Iris (standing) as part of a "Think Tank" at Paramatta, NSW, in 2007. They are flanked by (from left to right) Jenny Green, J B Munro, Susan Kerr and Philippa McDonald.

On June 9 last year, Iris died after a short illness. After that, Ray's own health declined.

They left behind a large extended whanau, and for us, many happy memories of a life full of hard work hand-in-hand with good company and fun.

Susan Kerr

More Memories

Polio News editor, Mervyn Dykes, first made contact with Ray Wilson around 2006 when he was seeking information for a newspaper story.

"I was writing about the anniversary of a Polio vaccine and needed the name of a good contact in the Manawatu," said Merv. "Ray was courteous and helpful. He gave me the contact details for Raylee Murphy in Feilding and I got a good interview little realising that I had made a valuable new friend.

"Barely three years later, the sudden death of my youngest son triggered the emergence of intense post-polio effects. Raylee's voice of experience was an immense help in guiding me through these awful times. That was another legacy from Ray Wilson."

Memories From Claudia Mushin and Philippa McDonald

Ray was President of the Board of Polio NZ when we first joined the Board in the early 2000s. We worked together for a number of years.

He was President at a time of change for Polio NZ when there was a need to unify the various branches and groups. To help with this he brought skills of quiet leadership, warmth, and a capacity to encourage others to show initiative and contribute to the Board's work.

Under Ray's Presidency a Futures Group was set up including us and Jim Webber to look at how Polio NZ might move forward. Ray also made contact with Mary-ann Liethof in Melbourne. This fostered a relationship which has lead to strong ties with Australian groups.

During this time we first came to meet Jega.

(Continued Over)

Tributes to Ray Wilson

(Continued From Page 7)

Under Ray's Presidency Jega was invited to New Zealand to speak to our members, and the relationship has strengthened and developed ever since.

Another standout feature of Ray's leadership was his personal wish to make contact with every group or branch in the country if possible. He spent many hours travelling to groups large and small to seek out members' views, and make the Board familiar and approachable. This was much appreciated in the groups we visited.

There was also another aspect of Ray's presidency which was very noticeable – the quiet help he received from his wife Iris who travelled with Ray when she could, and usually attended conference.

If we couldn't speak to Ray at busy times the fall-back option was to seek out Iris and ask for her help to catch his attention.

This always worked.

As many know, Iris died not long before Ray.

They are remembered with affection and missed.

Raymond Leslie Wilson QSM

Good Results at Pioneering Triplaner Orthotics workshop

By Gordon Jackman

The Triplaner Orthotics workshop held at QE Health in Rotorua with Marmaduke Loke went very well.

The workshop was attended by 15 orthotists, four prosthetists, one physiotherapist and nine polio survivors, so the learning was reality-based.

Feedback for the orthotists and prosthetists who attended has been positive with almost all keen to attend the next course if we can arrange it.

As with any new technology, there were quite a few things we learned . Some of us who acted as polio models were probably too complex for the first level that Marmaduke was teaching.

The gait analysis normally requires many hours and careful analysis of observation and video of gait, so that process was shortened for all of us.

The process of laminating the braces is technologically complex and exacting, Teaching it probably required more time and less pressure. Nevertheless eight braces were successfully cast and made, however, as we are all finding out, it takes considerable time, perseverance and endurance to learn to master these braces.

The new body alignment is quite different and learning to walk "normally" after a lifetime of a compensational walking pattern is no instant event. Standing perfectly balanced with the whole body aligned for the first time ever is truly amazing and instant, and I will be persevering to get that feeling when I am walking.

I am keeping in touch with all of our polio models and trying to make sure that they each have the support needed to keep learning to use their new braces. A fuller report on the workshop is available on the polio.org.nz website.

More Scenes From the Rotorua Retreat

President Barry Holland checks out one of the many displays and presentations at the annual Polio NZ Retreat in Rotorua.

The Retreat was held at the QE Health complex and was attended by 56 polios from around New Zealand. It began on Friday, August 12 and continued until the afternoon of Sunday, August 14.

On the Saturday afternoon participants were invited to attend an open meeting of the Polio NZ Board.

On the Friday and Saturday evenings, dinners were held at nearby restaurants.

However, in spite of the many attractions at the Retreat, most attendees agreed that the highlight was being able to mingle with and chat to each other.

Two special guests at the Retreat were opera singer Dame Malvina Major and her brother, Gordon, who is a polio. During one of the afternoon sessions on Saturday, Gordon told of his life with polio with Dame Malvina acting as interviewer. Afterwards the two demonstrated an unusual talent they had enjoyed in their youth – yodelling. Yes, opera singers can yodel!

Sue labelled this shot “The Usual Suspects”. They look a mischievous lot, but make of it what you will!

Terry Falkner, deep in contemplation!

Around the Regions

Christchurch

At our AGM we elected a new committee of Barry Hollands (President), Doreen McCoard (Vice-president), and Carl Pascoe (Secretary/Treasurer), with Ray Willoughby and Alison Walshe as committee members.

The outgoing committee have undertaken sterling work over many years and their contribution to the Polio network is much appreciated.

Our AGM was well attended with 24 members and four non-members present to hear Barry Holland, the national President, talk to us about the National Board's view of the Almer Slack bequest.

It was great to learn that a small advisory group of two National Board members and two local committee members will make recommendations on how this gift is to be spent.

We also heard from Jessie Snowden, a local physiotherapist who described some possibilities for a 'clinic' service for polio survivors.

While the AGM was hard work at some points, we are now certain that we comply with all of the rules and laws that apply to being a branch of an incorporated society, Polio NZ.

At our October members' meeting we confirmed that Ray Willoughby and Barry Hollands will be the local representatives on the Almer Slack Bequest Committee. We also confirmed Alison Walshe as the Social Convenor.

There was good discussion in small groups about what we wanted from our members' meetings. In summary, our members want to continue the social side, have speakers about the medical and treatment side of polio including orthotics. They also want time to be given for members to share their personal stories.

We are looking forward to our annual Xmas party and wish all members of Polio NZ a very happy and festive season.

Manawatu

Polio News editor, Merv Dykes, and his wife, Tina, were part of a panel of speakers at a Rotary dinner in Palmerston North where enough funds were raised to protect 1358 children against polio.

Merv spoke from the point of view of a person with post-polio syndrome and Tina described the role of a care-giver. A third member of the panel was Bev Quinn, a nurse who once worked at the Duncan Home.

Convenor, Dr. Bob Stewart, said the host club, Terrace End, had only 23 members, but with three earlier dinners had raised sufficient funds to treat 10,377 children (assisted by a Bill and Melinda Gates Foundation 2:1 subsidy).

"Your statement was very much appreciated," he told Merv. "I believe that we all can be proud with how well everything went at the event. A lot of people commented to me that they felt their awareness of polio had been substantially enhanced as a result of the evening."

The Manawatu group also held a successful lunch gathering in Feilding in October.

Yet another shot from the 2016 Retreat, which certainly brought people together from Around the Regions. Here they pore through items in a display of mobility aids.

Duncan Fund Guidelines

The Duncan Fund programme of Polio NZ Inc. is made possible because of generous donations from the Sir Thomas and Lady Duncan Trust. Its purpose is to assist in addressing the needs of those living with the long-term effects of polio, for which no other funding is available.

The qualifying criteria for this assistance are as follows:

- The applicant is living with the long-term effects of having had polio.
- The applicant is in good standing as a member of Polio NZ Inc. (having paid their $10 per year sub).
- The applicant shall produce evidence or otherwise convince the Duncan Committee that the purpose of their application is necessary in the management of their post-polio condition.
- Other avenues for funding need to be investigated before applying to the Duncan Fund. The Fund is for where there is no other funding available, or possibly where alternative funding would take too long as to make it impractical.
- The purpose of the grant must be for the personal benefit of the applicant in managing the effects of polio.
- The terms of the grant shall be determined by the Duncan Fund Committee of Polio NZ Inc. The Committee may decide to approve partial or full funding of the application. The approval or denial of any application is at the sole discretion of the Board of Polio NZ Inc.

An application form for the Duncan Fund can be requested from:

The Secretary, Polio NZ Inc.,
PO Box 791 New Plymouth 4340
or e-mail secretary@polio.org.nz

Moments of Truth

By Mervyn Dykes

They say polio survivors tend to be Type A personalities – stubborn, bullish and often over-achievers. I certainly gave it my best shot when growing up as I tried to show people that I was better than normal.

I threw myself into sports of all kinds and played until I dropped. In my youthful arrogance I boasted “I can win any race so long as it’s long enough.”

Then, in my twenties I moved to Wellington. There I met a guy who said he’d been told I did judo. He had just started going to classes at the YMCA and wondered if I would be prepared to come with him as a sparring buddy. I agreed, and soon we were regulars at the Y.

As part of our training, we did randori, or free practice where you move around the mat and try to toss your opponent. I was rather cocky because I was better than him and usually won. One day though, he caught me daydreaming and made a good, clean throw. I was furious. How dare he!

I got to my feet, eyes blazing and slammed him to the mat so hard that if it was carpet he would have become part of the pattern.

As I stood over him, eyes still flashing and smoke probably coming out my nostrils, he looked up at me and said admiringly, “Good throw, Merv.”

Suddenly, my anger was gone. It was replaced by the flames of shame and embarrassment. I felt despicable and worthless.

I will never forget that moment and the lesson in humility it taught me. I try to keep that spirit with me and be gracious when others offer to help me because they love me, or are simply good people. It serves me well too in my dealings with my best friend, my companion and wife of more than 50 years who now has to live with an ego-blasted and athletically challenged post-polio.

Last Glimpses From the 2016 Retreat

Karen Butterworth of Waikanae, whose poem appears at right.

Gary and Lisa Janmaat during a happy moment at one of the restaurant outings.

A Parting Shot

Do you want to give yourself an early Christmas present? It's easy.

All you have to do is promise yourself that you will be at the 2017 Polio NZ Retreat which will be held at the QE Health complex in Rotorua on October 6, 7 and 8. The AGM will also be held that weekend at the Retreat

There will be lots to learn and enjoy, but by far the biggest treat will be to spend time with others just like you who understand.

Poet's Corner

I'm still here

August 1942

Isolation cell. The chipped plaster walls
painted cream and aqua press in
and down on me like Poe's pit.

Brisk footfalls doppler past.
In the door's small window faces loom and recede,
time absent but endless, punctuated by thermometers,

pulse-taking with pursed lips and pocket watch; recurring
queries about the movements of
some strange things called bowels,

to which I answer 'Yes' until the day of reckoning
when I must swallow a gelatinous green pill
the size of a stinky marble.

Once a week my parents' faces appear in the window,
but more often Plymouth Brethren who pray and leave me
pink pamphlets headed 'HELL! HELL!! HELL!!!'

December 1942

First wheelchair trip – bright scudding clouds.
Glory of sun and wind on face and limbs,
birds, bees, scent of jasmine.

A nurse helps me stand. I proudly shuffle towards
my mother, who holds a baby I've never seen
and asks 'Will she always walk like an old woman?'

January 2016

The love of my life pushes my wheelchair
amongst spring blossoms. Sun and wind caress
my face and splinted limbs.

Behind me stand summits: Mt Egmont, Milford Track,
degree, five careers and family, but never the
achievement of not walking like an old woman.

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