



Fieldworker Darian Smith catches up with Naera Haronga over coffee

A day in the life of a fieldworker

Here for members, families and whānau

Our fieldworkers work in the community providing personalised support and education for members with lived experience of a neuromuscular condition.

Find out what they may do on any given day.



talks about school visiting and attending clinics with members.

Sometimes it's easy to forget that a fieldworker isn't just there to work with the person who has the condition, but those around them as well. This can be family, and it can also be medical professionals, employers, schools and peers. Darian Smith, Northern Branch,



School visit

I often visit schools where a young member attends as a student. Part of the support we offer is to provide educational sessions about the impact of neuromuscular conditions for children and young people. These talks can be either for the school staff, or for the students, to raise awareness and support student participation in school life.

When talking to staff, I will sometimes use a PowerPoint presentation or, if it's a small group, simply provide them

with information and discuss with them what some of the experiences can be like living with a progressive neuromuscular condition, and how they can make their student's time at school easier. Usually parents have already discussed the situation, but school staff can sometimes find it difficult to understand the nature of neuromuscular conditions – especially the delayed impacts of physical activity such as fatigue and how that can be for the student in a school environment. School staff seem to value the opportunity to talk to someone neutral and ask questions.

When I'm planning to talk to the students themselves, I first ask the child with the condition how they would like to be involved. Some children like to be in front of the class presenting with me, others are happy to be named and discussed but some prefer not to be singled out or even not to be present at all. Any of these options is totally fine.

The session usually begins with a discussion about 'difference'. I point out that some of us need glasses to help our eyes see better, and neuromuscular conditions are like that but for muscles. I give an age appropriate outline of the condition, talk a bit about genetics and how conditions like this don't transmit to other people unless there is a family connection. I like to use a fun physical activity to give the children an experience of what it might be like to have muscles that don't work as well as they're used to. I ask them to brainstorm ways they could be inclusive and caring of someone with a neuromuscular condition and answer any questions they may have.

Studies suggest that peers who are educated about a student's condition are more supportive and less inclined to bullying and the anecdotal evidence from our members also supports this. It's a great way for us to make a tangible improvement to the school experience for someone with a neuromuscular condition.

Clinics

Some of our members attend neurology clinics. One of the ways I support members and medical and allied health professionals is to attend these clinics as well. Clinics vary across locations and may have a different focus. Some will be a simple appointment with a neurologist. Others will include a multidisciplinary team that may include

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a physiotherapist, occupational therapist and speech language therapist.

Having a fieldworker at clinic provides a variety of benefits. I'm there as a friendly face and support for the member, I can help prompt information and issues if necessary, and can be a good source of information for any health professionals who are new to the neuromuscular field. Even more importantly, the ability to be adaptive and holistic in approach means I can follow up on a variety of issues that come up, which the doctor may not have the time or ability to deal with. For example, support and information on funding sources, social supports, school support, green prescription, employment, Total Mobility card and many other issues may come up in the course of a clinic appointment but be outside the purview of the health professional to do much about within the allotted timeframe of the appointment. As a fieldworker, I can make suggestions and provide ongoing support outside of the clinic, and ensure these things are resolved.



Fieldworkers visit members in their homes, or a public place such as a café or a library if they prefer. It's a chance for one-on-one time with a professional. Jo Smith, Southern Branch, talks about getting the most from a home visit.

Home visits

Our role is invaluable in that we come into a member's home and see them in their own environment for an hour – you don't get that from many other health professionals.

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People welcome us into their own home so it’s very important that we establish a rapport with them and meet at a time that suits them. It’s their time, they’re in charge and we follow their lead.

To begin with, we may ask lots of questions to get an idea of what is important to people, the kinds of challenges they may face and how we might be able to assist. I’m there primarily to listen to what people have to say. Every individual has a story to tell, and by listening to that story we can often work out where we can help most. Then it’s a case of prioritising what’s most important to them at that moment. It may be issues with pain, or fatigue, or social isolation. Because we work with progressive conditions, it’s also important to talk about what may happen next. If you have a plan, often the future is not so daunting.

We are solution focussed and work closely with the member to make sure they are happy with any further steps. Personally, I love being able to leave a member’s home knowing there is something we can do that will make their life better. Often it’s about exploring options that people may not know exist and facilitating solutions that work for them and their lives. I am constantly inspired by the people I visit.



About half of a fieldworker’s time is spent making referrals to other agencies on behalf of a member and supporting them through the process from referral to outcome. Fieldworkers often refer members

and advocate on their behalf with various medical and social agencies such as physiotherapy, occupational therapy, needs assessment & service coordination agencies, genetic health services, Housing New Zealand and Work & Income NZ. This is always done with member’s consent. Dympna Mulroy, Wellington Branch, explains more.

Referrals

The health system can be difficult to navigate your way around, especially if you are new to it. Some people aren’t aware of all the potential supports and services available and it is important to have someone who can walk alongside them on this journey. Letting people know about the support they are eligible to receive and how to access it, enables them more control over their health, and well-being.

Many agencies don’t accept self-referrals and some people don’t want to go to their GP for a referral given the associated cost, so as trained healthcare professionals we are often able to refer our members to services provided by these agencies. If not, we can advise and help them access it through other means. We are also able to provide accurate and relevant information on a member’s rare condition so the agencies are better able to acknowledge and appreciate their needs.

I get lots of positive feedback. I remember helping a member who had been struggling to get in and out of his home because of uneven steps. Previous referrals to occupational therapy had not been successful and he felt the only remaining option was to move. In the meantime he was at risk of falls and injuries. With his consent, I sent a referral to the occupational therapy department requesting they reassess this gentleman’s external access and consider a handrail as an alternative means of support. A few months later he rang me to thank me for my support. He explained that the handrail had made a significant difference to his ability to safely access his home.

Unfortunately not all outcomes are positive, especially if someone does not receive the support they hoped for. In these circumstances we support the individual through the process, identify the reason for the outcome and look at what to consider for the future.

A great day at work for me is one when I see someone

achieve a goal. I love seeing someone smile feeling that we have been able to help them have more freedom and choice in their life.

Advocacy



Having someone on your side who can offer support and speak up for you when needed makes all the difference. Advocacy is an important part of the fieldworker's role and Penny Piper from Wellington Branch explains how her job includes everything from going

to a WINZ appointment to writing letters to landlords.

Being an advocate for someone is letting them know that there is someone else walking that road alongside them, who holds their best interests and goals at the forefront.

An advocate can speak up for you if you are feeling a bit overwhelmed and also encourages others to value those with needs different to those of the general population (special housing needs is one example of this). When facing new or challenging situations, having an advocate can also help people deal with feelings of isolation or confusion, supporting them to achieve their desired outcome.

I always talk with our members about what they want and what steps are needed to reach that goal. Then we decide what they would like to do themselves, and what they would like support with.

I may attend WINZ appointments to ensure all entitlements have been discussed, or write letters to landlords, WINZ, and support professionals. Sometimes I help raise issues with carers/agencies, or support conversations with family members that may be difficult. As fieldworkers we support carers and family members who need advocacy too.

Members make comments such as; "I'm so glad to have had help with this", "I'm pleased with the results and next time I would just get on to it sooner", "That's usually been scary for me, but I felt like they heard me when I took a support person", "It was good you reminded me of what I wanted to say".



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Getting calls or emails that let me know the things we have been working on have been realised is very exciting for me. I get to see firsthand the difference our planning and working together has made.

Regional visits



Our branch offices are based in the main centres but our fieldworkers visit members wherever they live. Much of their time is spent on the road. Marty Price covers Nelson, Golden Bay, Marlborough and the West Coast as far south as Franz Josef and explains what goes into planning a regional visit.

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I do a fair bit of planning before heading away, contacting members to organise dates and times and working to see if I can fit all members in on the days I am in the area. I try to see four to five members in a day when away and it can be a juggle at times.

It is important to have time in between visits, for reflecting and preparing, plus having some downtime. Keeping track of documentation and making sure any member information is privately secured whilst at the next visit also takes some managing.

Some members live in very isolated areas, but one of the great things about our service is that we offer it to everyone, regardless of where they live. Some members choose not to have a visit from a fieldworker, which is a personal choice that we respect.

Traveling long distances and in isolated areas means our mobile devices go off the grid and we may drive some distance without seeing other people or towns. Safety and access to professional support is an issue, so keeping in regular contact with our manager or another fieldworker is important.

A lot of members express their appreciation about the service we provide. They appreciate us assisting them with things that they haven't had the resource, support or information to achieve. They also tell me that having someone to speak to who understands their condition is really important and they are glad they can get this from their fieldworker. Members want this level of understanding from their GPs and hospital staff, but don't always get it.

It's a good day when I can walk back to my car still seeing the smile on the face of the member I just visited.

During our visits, I find people just release their thoughts and frustrations and sometimes we come up with a plan of what to do next. But even if there's no plan to follow up, it's good to know I was there to listen.



Professional development



While fieldworkers work alone a lot of the time, they are part of a team and check in with each other regularly to maintain best practice and keep up to date with new developments in research and treatment. Paul Graham, Canterbury Branch, explains how.

It is important to check in with other fieldworkers, either on a one-on-one basis, or via our regular teleconferences. I hear what is going on in the other regions, and can run questions and issues past others, who may have ideas on what to be mindful of with a particular condition or how to best approach a particular problem. These catch-ups are rather like working in the same office. It is very helpful to be able to talk to another fieldworker and compare notes. It can be a relief to know that I am not working alone and also good to get acknowledgment for the things that I am doing well. I can also contribute to, and share in other's learning, which is great.

We all attend training sessions at National Office a few times a year and we each maintain a professional membership with an affiliated professional body, depending on our base training and discipline. Our team is proactive about professional development.

The MDANZ Fieldworker service is offered free of charge to MDANZ members and is funded through donations and grants. Contact your local MDANZ Branch to be put in contact with your fieldworker.