

## Wellington Community Advisor update May 2019 – August 2020

*For Wellington MS AGM report*

The MS Wellington Community Advisory Service covers Wellington, Porirua, Kapiti Coast, Hutt Valley, and Wairarapa. This service used to be called the Field Worker Service. The change of title to 'Community Advisor' better reflects the nature of the role and service proposition for clients. Our team has 1 full time, and 2 part time Community Advisors. The team consists of Gillian Fry (in the role for 8 years; Medical Laboratory, Naturopathic and HR background); Katherine Jourdain (in the role for 3 years; Dental Therapy and Research background). Shona Daube (in the role for 1 year; nursing and management background)

Community Advisors work on client request due to the large number of clients, at a place that suits them. We hold 7 monthly support groups and clients can access an adapted weekly yoga group in Tawa. The city networking group meets once a month in the CBD allowing those who work have access to a lunchtime meeting. We have 9 regular attendees who find it a good source of information sharing and connecting. The Men's network in Kapiti is going well and meets once a month and has around 6 regular attendees who have also connected now outside of this facilitated network. A Kapiti women's network is being established aimed to meet the needs of younger women with MS who may be working.

Community Advisors receive referrals from, PwMS, Neurology and medical and allied health teams. We maintain good working relationships with health teams to focus on providing appropriate and effective support for PwMS and their families and whanau in the community. We provide wide ranging advocacy services. Some of these include advocacy with WINZ, Residential Care facilities, GP's, Social Workers, MP's, Mental Health teams, and NASCs (Needs Assessment Service Centre). We have attended NASC meetings and sought networking opportunities within the DHB Strategy and Contracts areas as well as MOH Disability Support Services. Requests for MS education in residential care has increased this year which has been a good way to increase awareness of MS in the community. We hope this education improves the care and understanding our clients receive in their care.

In May and June of 2019, MS Wgtn, in conjunction with Well Elder, facilitated a 2 day workshop for Carers. The workshop was well attended and gave carers the opportunity to connect with others over similar experiences, gain resources they can use in their caring roles and to have some time reflecting on their own well-being.

A women's wellness event was facilitated in Upper Hutt in 2019 that was very well attended with excellent feedback. This workshop was made possible by the donation of the venue from the Upper Hutt Cossie Club and donations from a number of local businesses. A newly diagnosed workshop was conducted in March 2020. It was held the week before lockdown so numbers were quite small but it was an excellent day with really good networking and feedback from participants. A support group evolved prior to the Workshop and has continued for those who want to connect with each other. This has been a great way for our Newly Diagnosed clients to provide support to each other and share information.

Within the Wairarapa, it was identified that the dispersion of new information to PWMS was not as comprehensive as could be. Those who did not attend the regular support group meetings, receive updated information from the newsletter but as this is only sent out three times a year, it was felt that this could be improved. A colourful, brief and region specific bulletin board is sent out monthly, to all clients on the data base, giving them an update on any local, greater Wellington and national information relating to MS and MS Wellington. A monthly radio programme on 'Living well with MS', was commenced on the local community radio station. The interviews are currently being converted to podcasts which will be made available from the MS Wellington website.

An MS Expo was planned for September 2020 but has been put on hold in light of the current environment. The Expo is designed to be a positive and proactive event based around sharing knowledge, resources, tools and networks. We are hoping to continue the planning for this event in 2021. ‘

Towards the end of 2019 Ocrelizumab became Pharmac funded for Relapsing Remitting MS that still fits within a certain criteria. This is very positive for Pw RRMS who fit the criteria and a large number of people have been switched from their current therapy to Ocrelizumab. Unfortunately it is still not funded for Primary Progressive MS. MSNZ are advocating for further loosening of the funded criteria and for funding PPMS. Medical cannabis remains even more topical with questions around suitability, efficacy and side effects of using this as a treatment for managing some MS symptoms. Studies that have been conducted are generally on THC and CBD and point to indications in chronic pain and spasticity. The results of the upcoming referendum will be interesting to follow.

All Community Advisors have been reviewing client databases this year attempting to make contact with every client, be it by phone, email or face to face visit. The overall purpose of this is to ensure PwMS in the Wellington region are aware of our service and get help if they need it. This has been quite a bold goal as it does involve additional work from our ‘on request’ service but is rewarding when we do reconnect with people to check in on how they are doing.

A big positive over the last year has been the free online MS education provided by the Menzies Institute in conjunction with the University of Tasmania. This course was very beneficial to our team who have either completed it or are registered to do it. A large number of clients and health professionals have also taken part which is a great way of being better informed and in raising the awareness and profile of MS.

Our Advisory service has continued during the Covid-19 lockdown but has become a remote service, working from phone, email and video conferencing during alert level 4 and will remain this way in alert level 3. We have been in touch with our most vulnerable clients individually as well as emailing communication updates around MS, Covid-19, and Neurology services, Social Services support and mental health support to our clients and members. We have liaised with regional council welfare services to arrange essential goods for some clients during this time. Largely it is remarkable and inspirational at how well our clients are coping during this time. It also highlights the ‘lockdown’ of a different sort that the likes of MS, disability, and chronic health can have on a person and how they need to cope and adapt to change and face challenges on a daily basis.

We would like to thank our clients, we appreciate working with them and the amazing skills and attitudes they have. We are constantly inspired by and learn a lot from our clients! Thanks to our Committee for their generosity in donating their time and skills to operate Wellington MS and in supporting us in our roles, and thanks to our Executive Officer, Catherine Stewart for all her work and support. We would also like to thank the members of DHB Allied Health/Rehab and Neurology teams, members of the Needs Assessment Service Centres, Mandy O’Neil who provides our professional supervision, and our Patron, Professor Anne La Flamme. All these people help us in creating positive solutions for our clients and make a difference in the MS Community.