



**MUSCULAR DYSTROPHY
SOUTH AUSTRALIA**

Client SERVICES Newsletter

**MAY-JUNE
2015**

Buddy Up

Did you go to Camp Capacity? Did you meet some volunteers at Camp that you would like to see more of? If so, why not become a part of our Buddy Up Program. Buddy Up involves 1:1 interaction between clients and volunteers. The program provides a social opportunity for clients to be able to get out and enjoy themselves. Buddies can choose to either spend time at the client's home playing games, chatting and having fun or go on an outing, for example to see a movie or to enjoy a meal. The Buddy Up Program is for clients and volunteers of all ages and we welcome new people to join. **If you would like to get involved, contact Client Services on 8234 5266 or email hteimorzadeh@mdasa.org.au**



Limb Girdle Muscular Dystrophy

Limb girdle muscular dystrophy (LGMD) is the common name for a diverse group of conditions affecting the voluntary muscles, mainly around the pelvic (hip) and shoulder regions. Different types of LGMD vary in severity, age of onset (when symptoms are first noticed) and how they are inherited. The variation seen in the LGMDs is caused by the differences in the type of gene alteration. Client Services can provide clients diagnosed with LGMD, parents and family members with information and support about the condition. Client Services can also source related research and findings. **If you would like information regarding LGMD contact Client Services on 8234 5266 or email aotoole@mdasa.org.au**

CMT & SCA Support Group

Muscular Dystrophy SA facilitates a quarterly support group for individuals diagnosed with Charcot-Marie-Tooth Disease (CMT) and their families/Carers of all ages. The aim is to share knowledge, experiences and gain new information from invited guest speakers. The next group will be held on Tuesday 16th of June from 1:30pm-3:30pm at the Muscular Dystrophy SA office; 36-38 Henley Beach Road, Mile End. The CMT group also extends an invitation to individuals who have been diagnosed with Spinocerebellar Ataxia in replacement of the SCA group that would otherwise be held on Wednesday 10th June. **If you would like to join us on the day, RSVP to Hoda on 8234 5266 or email hteimorzadeh@mdasa.org.au. Snacks, tea and coffee will be provided. Please advise of any dietary requirements.**



Grown Up's Getaway

It's that time of year again! Muscular Dystrophy SA is now taking expressions of interest for our annual Grown Up's Getaway. Grown Up's Getaway is a three night, four day holiday held at an accessible location, generally a holiday park, situated in South Australia. The Grown Up's Getaway is for clients aged 25 and upwards who have been diagnosed with a neuromuscular condition and their carers/family members. This year's Grown Up's Getaway will be held in mid-late October. We cannot give away any more details, other than the fact that it will be another well-spent, enjoyable, relaxing weekend that the Client Services Staff members are already looking forward to. **To register your interest, contact Client Services on 8234 5266 or email hteimorzadeh@mdasa.org.au**



Physiotherapy

Physiotherapy provides many benefits; it largely improves a person's posture control whilst also maximising an individual's functional independence. Through Muscular Dystrophy SA, clients can access one free physiotherapy appointment per calendar year with one of our preferred neuro-physiotherapists. This is a great opportunity for clients to develop exercise programs and discuss the use of aids or equipment as required. Clients can also utilise the Chronic Disease Management Plan to gain up to five rebated physiotherapy appointments per calendar year. Muscular Dystrophy SA will then cover the remaining gap. To arrange your physiotherapy appointment, **contact Client services on 8234 5266 or email kmclean@mdasa.org.au**

Carers SA

Caring for someone can be a difficult and isolating challenge, but it does not need to be. Carers SA is an organisation that dedicates itself to providing care and ongoing support to family members and friends of individuals who are living with a disability, mental illness, chronic condition, terminal illness or who are frail aged. Carers SA runs a Carer Support Program, providing emotional and practical support to carers. Through this program, carers SA provides local connection to support and other carers in your community via support groups. Support groups are held all over South Australia. **To find out more information about Carers SA and these support groups, go to www.carers-sa.asn.au**

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Supporting End of Life Decisions

Palliative care is the relatively new name for the specialised way of providing supportive care for any person with a life-threatening illness approaching the end of life. It is available for everyone, young and old, people of any ethnic or cultural background, wherever they live – in the city or in the country. The Palliative Care Council SA is the peak body for palliative care in South Australia. It is a member organisation of the national peak body, Palliative Care Australia. The World Health Organisation has defined Palliative Care as an approach that improves quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. The Palliative Care SA website announces news, events, online information, publications, learning opportunities and has links to other relevant websites. **Go to www.pallcare.asn.au or contact 8271 1643 for more information.**

Essential Medical Equipment Payment

The Essential Medical Equipment Payment aims to help eligible households impacted from the carbon price rise on everyday expenses. To be eligible for this payment, you or your household must have a person living with a disability, or suffering from a medical condition who uses specific medical equipment. The payment of up to \$147 annually intends to help households pay their energy costs if the usage of medical equipment results in households having higher energy expenses. **For more information to see if you are eligible for the Essential Medical Equipment Payment, visit <http://www.humanservices.gov.au/customer/services/centrelink/essential-medical-equipment-payment> or contact Client Services on 8234 5266.**

Australian Council Invests in Arts and Disability Leadership Development

The Australian Council is offering up to 10 arts leaders with disability the opportunity to join the Sync Leadership Program, providing a focus on the interplay between leadership and disability. The Australian Council has a number of arts leadership programs. They felt it was important to provide a program that is specifically aimed at artists and art workers with disability, with a view to enhancing access to leadership roles across the sector. The program will be held from 12 to 16 October 2015, providing training through a five-day residency in Adelaide, followed by individual coaching sessions delivered by the two program creators and presenters. The Council is inviting expressions of interest

from cultural leaders and influencers with disability to apply for the intensive leadership program. It will again be presented by Jo Verrent, who created the Sync Leadership Program with Sarah Pickhall, and this year Sarah will join Jo in Adelaide for the event. Applications for the Sync Leadership Program close on 2 June 2015. To apply, go to: <http://www.australiacouncil.gov.au/strategies-and-frameworks/sync-leadership-program/>

Cough Assist Machine

Muscular Dystrophy SA has one Cough Assist Machine that is available to clients to loan on a short term/emergency basis. Cough Assist Machines assists people by inducing both a slow inhale and a rapid exhale; this encourages natural coughing, whilst avoiding problems associated with more invasive procedures. Since Cough Assist Machines have been in people's homes, Muscular Dystrophy SA has identified a significant reduction in the incidence of hospital and ICU admissions, Emergency Department presentations, chest infections and visits to doctors. **If you are in need of the Cough Assist Machine, short term only, contact Client Services on 8234 5266.**

Computer monitors

Muscular Dystrophy SA has two Acer computer monitors to giveaway to clients. Both monitors are in good condition and will be waiting for collection at our office. **Contact Client Services on 8234 5266 or email aotoole@mdasa.org.au if you are interested in taking one of both of these monitors off our hands.**



Fundraising Events

Multicultural Feast

You are warmly invited to join us for an evening dedicated to celebrating delicious cuisines from around the world – on Saturday 27 June at Payneham Library Community Centre! Featuring a seven course menu provided by a selection of Adelaide's best restaurants. Wine, entertainment and a live auction, this event is not to be missed! Muscular Dystrophy SA will be subsidising tickets to this event at a 50% rate for up to five clients. The companion card will also be accepted. Contact Client Services on 8234 5266 if you would like to be considered to receive subsidised tickets. The selection process will be random to ensure fairness.

Entertainment Books

Support Muscular Dystrophy SA and pre-order your 2015-2016 Entertainment Book now! 20% of every membership sold contributes to our fundraising. Help us achieve our goal. If you would like to purchase a book through MDSA, call Gemma on 8234 5266.