

Michael always looked forward to attending Muscular Dystrophy NSW Camps: he would count down the days until he could go. He made many lifelong friends from the camps he attended. Michael also made friends from Boccia, and he was a very competitive team member.

The Melhuish family wish to express their heartfelt thanks to all those who have given their support, compassion and love throughout not only this very difficult time, but throughout Michael's whole life.

We are sure that all who knew Michael are extremely grateful and privileged to have Michael as part of their lives, and how better our lives are from having him in it.

Michael's smile and his eyes lit up a room, and that will be greatly missed by all. Michael was adored by his family and friends and it is a testament to him to see how many people attended his funeral to farewell such an incredible young man.

And to conclude ...

We will see you later mate, you will live in our hearts forever ... MAY THE FORCE BE WITH YOU MICHAEL!

MS Centre 80 Betty Cuthbert Drive,
Lidcombe, NSW 2141

Ph: 98885711 or Freecall 1800 635 109
info@mdnsw.org.au

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Talking Point

MUSCULAR DYSTROPHY NSW E-NEWSLETTER WINTER 2017

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Welcome from the New Event Coordinator

Hello Louise

Welcome to the second online version of our Talking Point Newsletter. My name is Mitch Taylor.

I am so happy to join the Muscular Dystrophy NSW (MDNSW) team and I can't wait to meet you all. I've really felt welcomed here, and I look forward to what the role has to bring, which includes organising and running camps, coordinating the Duke of Edinburgh's Award and putting together Talking Point.

If you have anything interesting you would like to contribute to Talking Point, please get in contact with me. You can email me at mitch.taylor@mdnsw.org.au or call me on 0458 026 532.

A little about me:

I've worked mostly in the sport and recreation area throughout the approximately 20 years that I have worked in the disability sector. I enjoy all aspects of sport and recreation both in my work and leisure time. I am extremely passionate about the Duke of Edinburgh's Award, having been an award Leader in the past. I truly believe in the positive outcomes that participating in the award can bring.



In my spare time, I love to watch most types of sport, and I play soccer and touch football. I also enjoy travelling and camping when possible. Otherwise I love to spend time with my four young girls and my wife.

2017 Tax Appeal

A huge thankyou to all those who donated to this year's tax appeal. Without your generous support the work that MDNSW do could not continue.

Free NDIS Planning toolkit from MDNSW

MDNSW has developed a **free downloadable toolkit** specifically for people living with a neuromuscular condition, to help you prepare for your first NDIS Plan. It can also help you plan for your 12-month NDIS Review. Download your free copy of **My NDIS Toolkit now**.

If you'd prefer to have a printed version sent to you, please contact us.

Your choice - Co-ordination of Supports

One of the primary services MDNSW provides under the NDIS system is Coordination of Supports. Coordination of Supports helps you implement your NDIS plan by finding the relevant services that you need, specific to your situation.

MDNSW is different from other providers. We provide services for people living with a neuromuscular condition only, while most others provide services for a variety of disabilities.

Why should I choose you to do my Coordination of Supports?

We have a team of professionals who have specific skills and knowledge in assisting people with Neuromuscular conditions. It's what we do best and this knowledge and experience is essential in connecting you with appropriate qualified service providers.

Because we take a whole-of-life approach, we also build lifelong relationships with you and your family which may not be offered elsewhere.

Celebrating the life of Michael Melhuish

7th NOVEMBER 1989 – 5th JUNE 2017

Michael will be remembered for many things, but two traits everyone would agree on were his strength and compassion. We have fond memories of Michael always giving everything a go and looking out for others.

When Michael turned three, he was diagnosed with Duchenne muscular dystrophy (DMD).

Michael completed Year 12 and received his Higher School Certificate. He then continued on to TAFE, studying Information Technology. In 2009–2010 he achieved the Most Outstanding Graduating Student, which was a very proud moment, not only for himself, but also for his family and his teachers. Michael went on to become a website designer, creating websites for local businesses including the Parkes Show. He also completed the Duke of Edinburgh's Bronze Award through Muscular Dystrophy NSW.

Michael was a fanatical Parramatta Eels supporter. Michael organised a fundraising and awareness day for Muscular Dystrophy NSW. With his friends and family they travelled from his hometown of Parkes to Parramatta stadium raising awareness of Duchenne Muscular Dystrophy. The event also raised \$22 000.00 for MDNSW.

Michael was one of the most caring people with the biggest of hearts. He was the strongest person that you would ever meet who always saw the best in life. The most loyal and reliable friend, he was always there if someone needed to have a chat, giving the best advice he could to help out. He loved his family and, given the choice, wouldn't have wanted to be anywhere else but spending time with them.

Michael always looked forward to attending Muscular Dystrophy NSW Camps; he would count down the days until he could go. He made many lifelong friends from the camps he attended. Michael also made friends from Boccia, and he was a very competitive team member.



Find out why kids
keep coming back
year after year!

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

Camp Kula N' Gadu 2017

WHEN & WHERE?

Sat 16 - Wed 20 Dec

Sydney Academy of Sport
and Recreation, Narrabeen

WHAT?

Participation in a huge variety of unique activities. All meals, accommodation and equipment hire. There will be at least one carer to each camper and a nurse on site.

WHO CAN COME?

This camp is open to people aged 6-18 with a neuromuscular condition. Activities are age appropriate and cater for all levels of skill and ability.

WHY?

Because it's the most fun you can have in five days. Make new friends or catch up with old ones. Have a break from Mum and Dad!



How MUCH WILL YOU PAY?

\$120 (this is an administration fee paid by you and is not covered in your NDIS package)

NDIS FUNDING

The cost of the camp will come from your NDIS plan in the CORE supports area.

Please contact us if you're unsure if you have funding for camp in your plan.

If you are in the process of getting ready for your planning meeting we can provide you with a quote to request funding.

WANT TO REGISTER OR FIND OUT MORE INFORMATION?

Please contact Mitch at
mitch.taylor@mdnsw.org.au
or on 0458 026 532

*Remember, this is a popular camp
and takes a lot of organisation so
please register ASAP!*



mdnsw.org.au

I'm unsure of what I do next. Can you help?

If you're in the planning stages and are not sure what Coordination of Supports is or what to ask for, please contact us on 1800 635 109.

It's very important to note that you have a choice in who you want to receive Coordination of Supports from. This is the same for every part of your NDIS plan. You can change providers whenever you like.

If you're with another provider but you'd prefer MDNSW to assist you with support coordination, please contact us today.

National wheelchair sport update

Have you been wondering where wheelchair sport is operating in your local area? Please don't hesitate to contact Mitch. He can connect you with a sporting organisation near you.

If you have an interest but you're not sure how to get started, MDNSW is here to help!

The Junior Wheelchair Soccer "come and try days" still have a couple of events left. It's not too late to give it a go! The dates are in the flyer to the right.

The wheelchair hockey competition will start in October. If you're interested in trying out or need help getting into a team, please get in contact with us. We'll send out the dates and details once they become available.

MDNSW now has six Boccia sets – including ramps, balls and instructions – to lend to schools, community groups or individuals free of charge.

We also have guards which you can borrow if you're interested in trying Power Wheelchair Soccer.

Are you over 18 and want to participate in a retreat or outings?

Please contact Mitch on 0458 026 532 or mitch.taylor@mdnsw.org.au to register your interest.

Welcome to our new Finance Manager Angelito Escalada

Angelito joined MDNSW as Finance Manager in May. He is an experienced accountant, with more than 15 years in the not-for-profit sector. He has held finance and accounting responsibilities in several areas, including schools and education, venues management, mission ministry, international aid, policy advocacy, remote aged care and community services.



"I'm really fortunate to have joined Muscular Dystrophy. There's so much to learn in the disability sector at this time. I look forward to having a more in-depth understanding of NDIS and its financial impact on both the association and its clients."

In Angelito's spare time, he enjoys watching movies and playing basketball with his sons, aged 16 and 9. He is also happy with MDNSW's recent move to Lidcombe, as this allows him to drop his children at school in the morning for the first time after many years of them taking public transport.

Professor Graeme Morgan receives Queen's Birthday honour

MDNSW extends sincere congratulations to past President of MDNSW Professor Graeme Morgan who was recently appointed Member of the Order of Australia (AM) for significant service to medicine as a clinical geneticist and paediatrician to medical education and professional organisations.



What impact did attendance at the weekend retreat have on you and your partner?

- It was so valuable to meet other couples who understand how NMC affects your life. Inspiring to meet others and to know we are not alone
- A weekend to connect with other couples in similar circumstances, share stories about our lives and form friendships. They are great!
- It was amazing to meet people with the same disability as you

Have Your Say!

Along with sharing the results of our last client survey we are also interested in learning a bit more about your experience communicating with us, here at MDNSW.

We are keen to learn about how you'd prefer to receive correspondence from us and what sort of information is of interest to you.

Please click on the image below to complete our short survey on communicating with MDNSW.

We really do appreciate it!

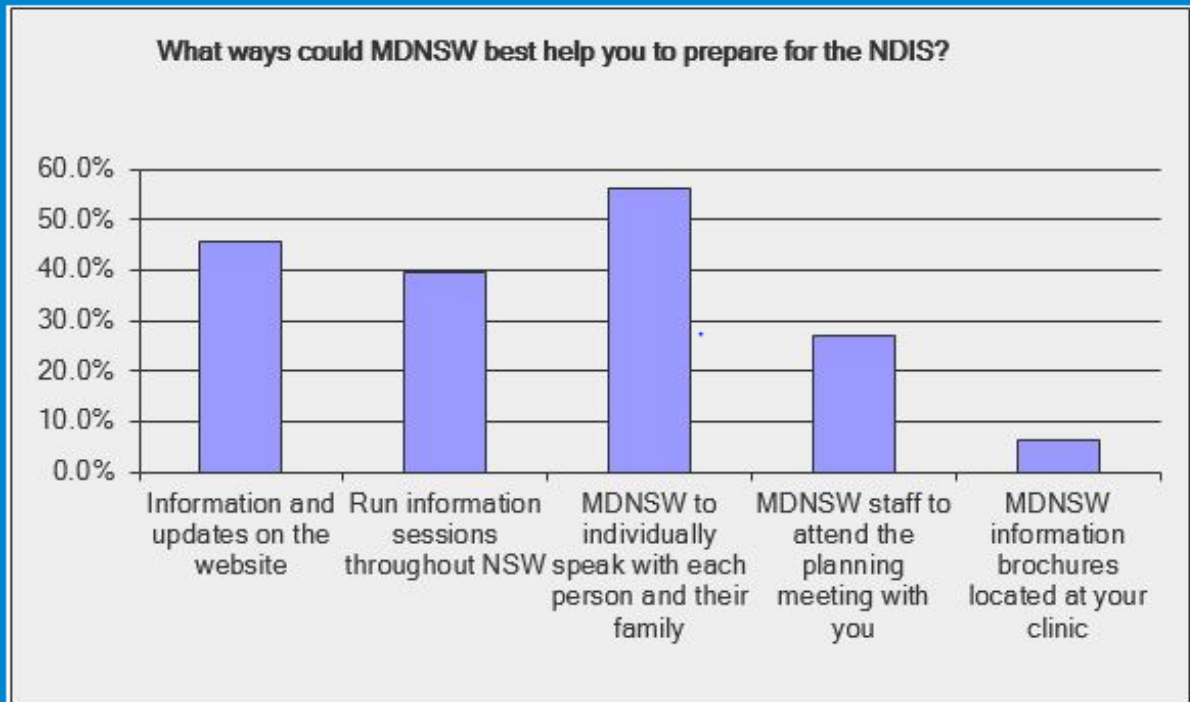
<https://www.surveymonkey.com/r/MDNSWCommunication>



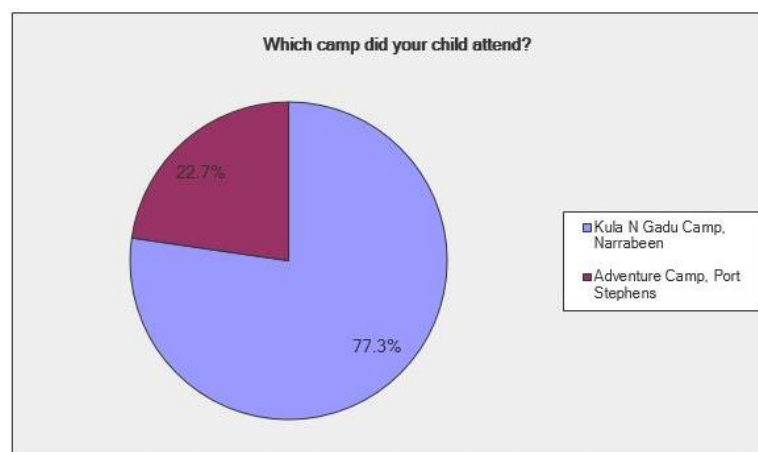
feedback

What ways could MDNSW best help you to prepare for the NDIS?

- MDNSW to offer one to one advice as part of preparation for NDIS
- Put information and updates on the MDNSW website, tips on Facebook
- Help me to prepare and attend the planning meeting with me to give me more confidence
- MDNSW usually has more idea about our condition than other service providers, so can help more with the supports we can receive



- How important was camp attendance to your child's development and socialisation?
- Essential!!
- Excellent as a confidence builder and to have a break from being at home
- The camps give the children an opportunity to think about, discuss and explore issues relating to their condition. But most importantly, they encourage independence, a positive outlook and FUN!!
- Making new friends, trying different activities, having a break from the normal routine



His service includes:

Sydney Children's Hospital (formerly Prince of Wales Children's Hospital)

- Emeritus Consultant Paediatrician, since 1998
- Head, Genetics Department, 1990–1999
- Founder and Chairman, Department of Clinical Genetics, mid 1980s–1999
- Associate Clinical Director, Division of Paediatrics, 1976–1990
- Established the Muscle Diseases Clinic, 1964
- Established the Genetics Clinic, 1963
- Former Chair, Ethics Committee

University of New South Wales

- Honorary Professor, School of Women's and Children's Health, current
- Associate Professor (Conjoint) Human Genetics, 1987–1998

Muscular Dystrophy Association of New South Wales

- Honorary Medical Director, 1965–1999
- Chairman, Scientific Advisory Committee, 1998–2003
- President and National President, 1998–2003

Other

- Consultant Geneticist, Neurogenetics Clinic, Concord Hospital, until 2014
- Consultant, pre-implantation genetic assessment, Sydney In-Vitro Fertilisation Service, until 2014

The Children's Hospital at Westmead (formerly Royal Alexandra Hospital for Children)

- Emeritus Consultant Paediatrician, current
- Honorary Consultant Physician, 1963–1998
- Professorial Registrar and Chief Resident Medical Officer, 1956–1963

Professional organisations

- Former Secretary (Paediatrics), Board of Censor,
- Royal Australasian College of Physicians
- Former Chairman, Written Examinations Committee, Paediatrics
- Chairman, Genetic Services Advisory Committee, New South Wales Health, 1987–1997[FMU1]
- Member, Research Ethics Committee, Sydney Area Health Service, for 10 years

Phil's study trip to Denmark

At just 19 years of age, Philip has done more than most people do in a lifetime. And he has achieved all of this, living with Duchenne Muscular Dystrophy.

A native Danish speaker, Philip is on a mission to learn about Denmark's innovative approach to disability services and to bring those ideas home to Australia, to make a difference for people living with a disability – particularly young people. Specifically, Philip plans to develop and bring home an Integrated Living model to enable young people with disabilities, lead a full life, in their own home.



Why I am doing this (in Philip's own words):

I went on a study trip in 2015 for three weeks where I learned a lot about Denmark's highly successful approach to disability services. But that trip only scratched the surface of the research I wish to undertake. That's why I am going on an extended study tour in 2017, to bring back from Denmark the latest, most innovative ways to fundraise, and the know-how to build integrated living communities and help disabled young people achieve their goals.

The Integrated Living model I've been working on will allow people with and without a disability to live together – providing care, a shared home and a full life within the community for all residents. It is a big idea and a massive plan, but we know it will work and we already have a plan of what the prototype will look like.

My dream is to build the Integrated Living prototype here in Australia, to become an ambassador for young Australians with a disability, and to help Muscular Dystrophy NSW find new ways to fundraise to continue their vital work.

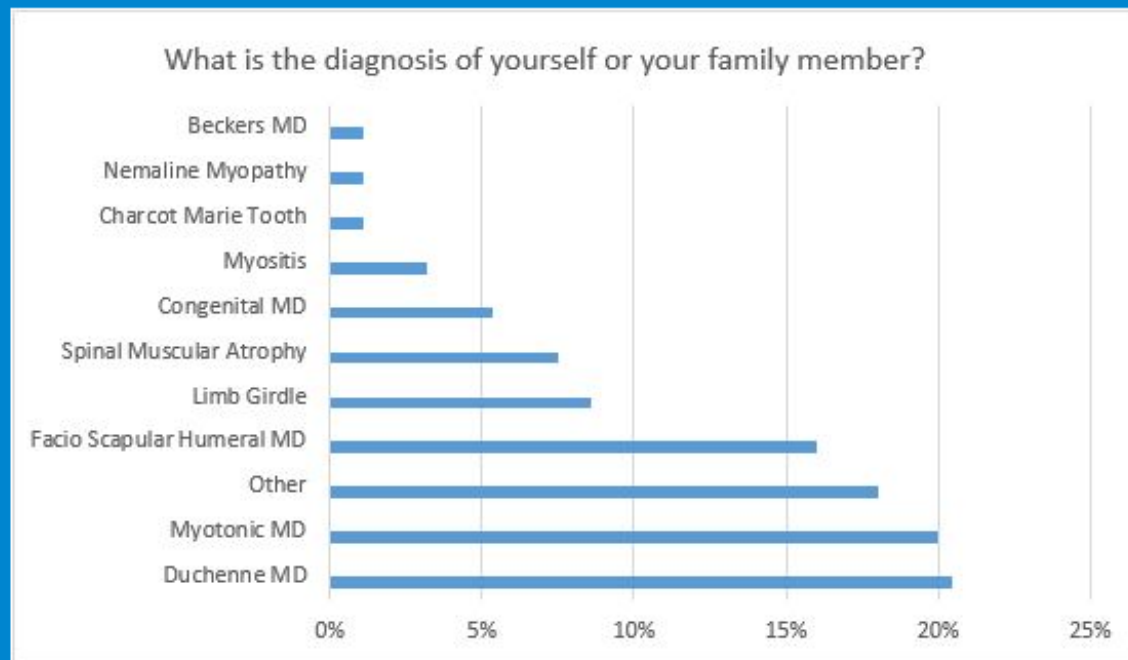
Best wishes,
Philip

PS There is also a website where I will be posting all about the project. Follow me at www.philipholsen.me.

MDNSW Client and Family Survey Results 2016

Thank you to the 99 clients and families who completed the survey.

We valued your feedback and suggestions and will be using them as we evaluate our current services and plan for the future.



In what ways have MDNSW services or events positively impacted you or your family's life?

- I have really benefited from connecting with other mums in similar situations.
- Camps and the Mothers Retreat have been amazing and such positive experiences.
- They have given a better understanding of services that will be available when required.
- Counselling was an extremely beneficial service for my anxiety/depression.
- Camp has had the most profound impact-it can't be missed!
- Has had huge benefits knowing that there are others with the same issues/struggles, great for connecting with others.

In what ways could we improve our services, programs or events?

- Perhaps programs /events for adults with MD as they are perhaps more isolated than the children
- E-news, more retreats and camps. Keep the great services and personal approach.
- Expand camp numbers!
- More rural and regional support when we need it throughout the NDIS process
- More information about upcoming treatments and expected clinical trials if any

MDNSW Team at our new Lidcombe office

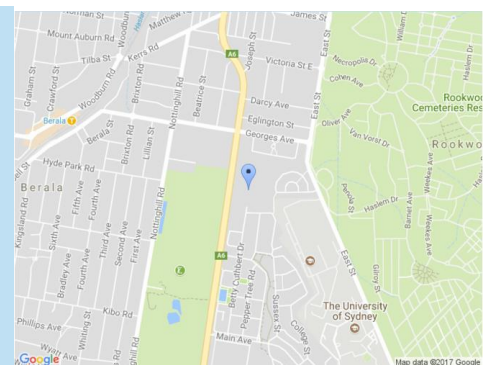


The Team from left to right: Louise, Angelito, Mitch, Maralyn, Alison, Jenny, Charlotte, Carolyn, Gracia and Joan

We are now located at the Multiple Sclerosis Australia Centre. It's central to Sydney and only 5 km to the M4, plus it's completely wheelchair accessible and has plenty of parking. But please note – it's only our address that has changed. Our phone number and email remain exactly the same. Come and visit us anytime during business hours!

Our new address

Studdy MS Centre, 80 Betty Cuthbert Drive, Lidcombe NSW 2141



Duke of Edinburgh's Award

We're in the process of recruiting new people to participate in the award and assisting those already in the award to move forward. It's for everyone from the age of 14 to 25, no matter what your limitations. Forget the idea that you need to go on a hike in the bush. There are many other wonderful ways to complete your adventurous journey or expedition. Like Scotty, pictured here, who went to New Zealand. I like to think of the award as a motivational tool to get you doing things you'd have never done otherwise. As the award Leader, it's my job to help create achievable goals appropriate to your abilities. We really want everyone to have a go. There are so many benefits, including bonus points for entry into some universities – it looks fantastic on your CV. It helps motivate you to achieve things you would not have done normally. Where possible, MDNSW will help with expenses.

If you'd like more information, please visit www.dukeofed.com.au or call Mitch for a chat!



Three weeks in Europe – Patrick Nolan & Roisin O'Hagan

I had been hoping and waiting for some time for this long-talked-of, big family trip to Europe. I'd dreamt of seeing Manchester United play for what felt like forever. My mum weaved some mum magic and secured tickets to a game. Woohoo, we are off on an adventure!

Friday 7th April 2017, we arrived. Was it utopia? No but close! Manchester UK, 23rd, blue skies and the home of the Red Devils. Mum had planned and booked this trip a mere 8 weeks prior, this involved ensuring that my 190kg powerchair was securely put into cargo hold and me in my seat of our Qatar flight, accessible accommodation

throughout the UK, France and Spain, a mixture of hotels and Airbnb, reserved seats on trains in Europe – an essential requirement of European train travel! There were of course obstacles along the way, we expected that, but those challenges were overcome with a little bit of innovation and humour!

Cancelled trains, no problem, inability to book wheelchair seats from Australia, managed. Having said that, I'm pretty sure we gave a couple of station masters near heart attacks rocking up with the powerchair, 6 people plus luggage, however the assistance and consideration we received was amazing. Every person we came across bent over backwards to get us on our way! We learnt the ropes, through a lot of sign language and pigeon French and Spanish and navigated the excellent and accessible public transport systems of the UK, France and Spain (including the metro in Barcelona).

This is what our 3 weeks looked like. A tour of Old Trafford, and saw everything Manchester United. Next stop, the Stadium of Light, Sunderland, where we watched Manchester United FC smash Sunderland FC. On to London, where I wheeled along many a Monopoly-board street, visited Hamleys toy store, cruised by Big Ben and Buckingham Palace, and of course indulged in the buffet breakfasts of the famous fry-ups.

The Eurostar (1st class as a wheelchair user) to Paris, fast pass up the Eiffel Tower (and looked at it from our loungeroom window a block away), ate cheese and beautiful baguettes, snails and frogs' legs, patisseries ... daily mouthfuls of pure ecstasy. Checked out the Arc de Triomphe, oh and caught an up-close-and-personal viewing of the Mona Lisa in the Musée de Louvre (the very kind security guard gave me special access). On to Avignon, the Pope's Palace (one of the few places I couldn't access), old paved streets, outdoor cafés and more glorious food, a day trip via train to Arles, another beautiful old town with a Roman amphitheatre (like the Colosseum).

Up next Barcelona, España, Gaudí's art – from the park named in his honour to Sagrada Família (just happened to be across the road from our apartment, very cool) – more delicious food, Catalan cuisine, yum! Our final but most spectacular destination, San Sebastián, oh the tapas ... San Sebastián was the most beautiful place in the world I've ever been to. We wandered the streets, checked out the Bay of Biscay, watched another football game, relaxing.

What a trip, sunny days, welcoming, helpful people, and the most wheelchair access I've experienced despite visiting cities and towns that are over 2,000 years old!

Young Persons Retreat

The retreat was held at the Parkroyal in Parramatta for seven people aged between 18 and 30 on the last weekend in May. Everyone arrived on Friday afternoon and were keen to settle into their rooms and then gather with the group to meet and chat.



Dinner on Friday night was in the hotel restaurant Table 30, where we all enjoyed a three-course meal. Everyone chatted and caught up with old friends, while some made new ones. They all agreed the rooms were beautiful and accessible. During dinner, we all decided that it would be a great idea to go to the city the following evening to see Vivid.

On Saturday morning, we enjoyed a buffet breakfast, despite a few bleary eyes, before spending a couple of hours discussing the Duke of Edinburgh's Award. We had a few extra Dukies join us for this session and it was good to hear stories of everyone's skills, volunteering opportunities, areas of physical activities and adventurous journeys. This session was followed by a yummy buffet lunch.

After lunch everyone had some free time, with some indulging in retail therapy, some hanging out together and some taking the opportunity to fit in a short nap.

We caught the 3.30 ferry to the city, deciding to take in the view and fresh air being such a beautiful day. It was a really pleasant way to travel to the city. Closer to the city, we passed a large boat and a massive wave crashed over the bow. Most of our group got a tad splashed! Scotty, Phil and Michelle got more than their fair share. After laughing it off we continued on our way, getting colder by the minute. After our final stop in Darling Harbour we were headed towards Circular Quay when it happened again – a huge wave crashed over the bow. Again, everyone was soaked. Scotty let out his trademark laugh, which was quite infectious. Everyone saw the funny side and had a good laugh.

We finally arrived at Circular Quay and made the decision to seek dry clothes. Everyone found a warm café to have dinner while Mel and Kejanna went shopping. Eventually they returned with some very smart tracksuit pants and jumpers. Thank you to Mel and Kejanna for the amazing effort they went to. Seeking clothing shops at 5.30pm on a Saturday in the city was a huge achievement!