



06

Chapter 06 – Holidays and fun

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In a nutshell – Holidays and fun

1 You can still lead a good life with DMD

When you are reeling from the shock of the diagnosis, this can be hard to believe.

But, as fellow DMD parents, we want to assure you that there are still many happy days in front of you.

We've shared our best recommendations for you and your family at the beginning of this chapter. We hope you'll find them helpful.

2 Music, sport, Cubs and pets

You'll find many wonderful opportunities for your child to play sports from swimming and hydrotherapy to adventure sports, like sailing, skiing and flying.

Many sports organisations for disabled people offer subsidised places at reduced costs.

Your child may also enjoy singing, learning an instrument or joining Cubs in their local area. And they may be able to get an assistance dog who will provide them with friendship and practical help.

3 Family holidays

For the next five years or more, you'll be able to keep enjoying the same type of holidays that you've had until now.

When your child's physical needs have changed, there are specialist holiday companies and holiday camps for people with disabilities. Some offer subsidised places too.

4 Grant-giving and wish-granting organisations

Starlight Children's Foundation, Make a Wish and other smaller organisations grant wishes for holidays and special treats to children with serious illnesses.

Some DMD families have used their wishes to go on amazing holidays to Disney and other places.

Starlight Children's Foundation also holds a wonderful summer party with rides, games and celebrities.

5 Fundraising together

Many DMD families fundraise for themselves and medical research. They often find that the contributions of their families, friends and communities provide valuable emotional support too.

Living a good life for your child, your family and yourself

You can still live a good life for your child, your family and yourself – although it probably doesn't feel that way right now.

Once the shock of the diagnosis wears off, you'll find a supportive DMD community ready to welcome you. And you'll discover many organisations that provide music, sport, holidays and adventures suitable for your child.

In this chapter, we have shared some of our favourites, but there are many more out there. You can find them on the internet or through your local council's advice service.

First, we want to share our three best recommendations for getting the most out of life with DMD:

1 Live in the present – Don't waste today worrying about what might happen in a year's time or ten years' time. Appreciate all the good things in your life and enjoy your son or daughter as the lovely child they are.

DMD does give you the opportunity to re-evaluate your life and focus on the things that are really important. So, try to live mindfully in the present and enjoy all the little things along the way.

2 Love matters more than anything else – Your love for your child is their greatest asset and will make an enormous difference in their life. Never doubt that.

3 You are not alone – The DMD community will help and guide you. The Duchenne Parent Zone on Facebook is a good place to connect with other families.

“My advice to other disabled people would be, concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit as well as physically.
– Stephen Hawking”



Brothers and sisters

When you receive the DMD diagnosis for one of your children, it can block out everything and everyone else - even your other children.

But as DMD parents, we encourage you to make time for your other sons and daughters too. All your children deserve and need one-to-one time with you.

Find something that they really like doing and try to give them your full attention. Tell your child that you want to spend time with them because it's fun – rather than making it a reward for being good or helping look after their sibling with DMD. They need to feel that they deserve your time in their own right.

You'll enjoy these special times together and so will they.

Make time
for your other sons
and daughters too

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Music, sport and movies

Children with DMD should have opportunities to learn music and play sports which they might enjoy.

For us as parents, it can be bittersweet watching our child playing an instrument or a sport which we know they won't be able to do so forever. So, the temptation for us is to 'protect' them and ourselves from this future loss.

But our children benefit greatly from developing their abilities. Not only will they have fun, they'll also develop their confidence, concentration and social skills.

Music helps develop their sensory, motor, social and expressive skills. And the right kind of physical activity is an essential part of strengthening and protecting their muscles.

So, we encourage you not to anticipate the loss of your child's abilities before it happens. Let them enjoy music and sport now, and worry about future activities when the time comes.



Music

Your child's own interests are the best guide when you are investigating different instruments and choirs.

If you can, let them try out a few so they can see which one they enjoy the most.

- **Learning an instrument** – brass instruments help develop the lungs and drumming can provide a great outlet for frustration. But any instrument will enhance your child's life.
- **Learning singing** – singing provides a good workout for the lungs and improves posture as well as being enormous fun. Singing in a choir or a band also develops children's social skills and lowers stress levels.

Beavers, Cubs and Scouts

Many children with DMD have had lots of fun and adventures in their local pack at weekly meetings, regional competitions, excursions and camps.

Some have reached high levels or received special commendations.

Scouting is an inclusive activity open to all young people, regardless of their mental or physical ability. You can see from their website that they try hard to make their activities available to all.

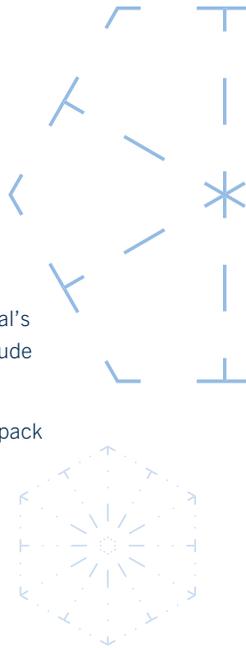
"Many young people will require some special consideration to enable them to fully participate in all Scouting activities. By identifying an individual's additional needs and providing them with appropriate support, we can include more young people in Scouting."

So, take a look at your local Cubs or Beaver pack and see how suitable the pack and location is for your child. Each county has a specialist SEN adviser and they can advise you which packs in your local area are the most suitable.

You do need to think about the future when you look for a pack. As your child progresses through Beavers, Cubs and Scouts, they'll need a location that will work for them as their needs change.

All the packs are staffed by volunteers. So, if your child needs extra support, you may need to volunteer yourself, or see if a friend or teaching assistant can attend pack meetings and camps.

We encourage you not to anticipate the loss of your child's abilities before it happens. Let them enjoy music and sport now.



Sports

Your child may enjoy these sports:

- **Soft play centres** – Strengthens children’s muscles and improves their balance while they’re playing and having fun. But you do need to supervise your child while they are climbing and sliding to make sure they are not over-doing it. Local councils and leisure centres often run soft play centres
- **Walking** – Improves children’s balance, especially when they are walking over different surfaces, such as grass, slopes and pebbles
- **Swimming** – Helps children to develop their muscle tone, balance and motor control. They can also stretch their muscles in a pool more easily than on dry land
- **Hydrotherapy** – Involves doing special exercises in a warm-water pool. The soothing warm water relaxes the children’s muscles so they can exercise more easily. Some parents invest in an inflatable hot tub, like a Lay-Z-Spa, so their child can do hydrotherapy at home. Hydrotherapy is often offered at hospices – and this can feel off-putting for parents. But we encourage you to contact your local hospice and ask about their services for children with chronic serious conditions. You may find they can provide other forms of support, as well as hydrotherapy, and many of their services are free
- **Bike riding** – Develops both sides of their body in the same way so it’s a particularly good exercise for children with DMD. Balance bikes (which don’t have pedals) can make good first bikes
- **Tomcat trikes (www.tomcatuk.org)** – Are specially designed for people with physical disabilities. But they are expensive. Many parents use GoFundMe or JustGiving pages to raise the money for a trike. Rotary clubs, charities, local schools and community groups have provided generous support to many families



- **Horse-riding** – Helps children to improve their posture, balance, co-ordination and communication skills. Children can complete badges and ride in competitions which also builds their confidence. Riding for the Disabled Association (www.rda.org.uk) is the best place to start
- **Tai chi and other martial arts** – Develops children’s body awareness and improves their general health through slow fluid movements
- **Sailing** – Suits children with a wide range of abilities as they can sit down on the boat. Take a look at Sailabilty which is run by the RYA (www.rya.org.uk), the Disabled Sailing Association (www.disabledsailingassociation.org.uk) and Sailing for the Disabled (www.sftd-iom.com) to see if they offer classes near you. You may even find they have subsidised classes
- **Learning to fly** – Gives children the opportunity to do something extraordinary which builds their confidence. Aerobility (www.aerobility.com) takes nearly 1000 people with disabilities flying every year. They offer half hour lessons which can make wonderful birthday treats
- **Ice-skating** – Many of the pop-up rinks that appear every winter will let children skate in their wheelchairs. The chairs also give parents something to hang on to which is useful!
- **Skiing** – Helps children to develop their motor skills and balance. Snowbility (www.snowbility.co.uk) and Disability Snowsport UK (www.disabilitysnowsport.org.uk) have centres in the UK
- **Disabled cricket, tennis, football, gymnastics, climbing and other sports** – Ask your local council about the sports and leisure facilities for children with disabilities in your area. And also ask them about community buddy schemes that may support your child as they take part in sports and other activities

Please remember that some activities can damage children’s muscles – especially scooters, bouncy castles, trampolines and rugby. These should be avoided.

Movies with a CEA Cinema Card

The CEA card (www.ceacard.co.uk) is a national scheme which gives a free ticket to a parent or carer who is accompanying a person with a disability (8 years old or over) to the cinema.

Your child might be too young at the moment. But it’s worth knowing about for when they’re older.

Assistance dogs

When your child is about 8-10 years old, they might be able to get an assistance dog.

These dogs help people with disabilities to maintain their independence by providing companionship, emotional support and practical help, like picking up things from the floor.

Assistance dogs make a big difference to family life and can increase the well-being of the whole family.

These dogs increase

the well-being of the whole family

Contact specialist

holiday companies and charities

Family holidays

Holidays are an important time for every family. You can relax and have fun together.

Your child is likely to be very young when they are diagnosed. So, you'll have many years where you can still go on the same type of holidays that you've been on before.

When their physical needs have changed significantly, you can contact specialist holiday companies and charities which have the facilities and services your family needs to have a wonderful holiday together.

As you might expect

The waiting lists for assistance dogs are quite long. So, it's worth contacting a charity while your child is still young.

Assistance Dogs UK is a good place to start:

www.assistancedogs.org.uk

- **When You Wish Upon A Star** (www.whenyouwishuponastar.org.uk) – A charity with properties in Cornwall, Alicante and Florida that are available for reasonable rents to families whose children have serious conditions
- **Calvert Trust** (www.calvertlakes.org.uk) – An outdoor adventure centre for people with disabilities that runs family and individual holidays
- **Holiday camps** – Your child may still be too young to join one of these holiday camps at the moment but it's worth bearing them in mind for the future
 - **Over the Wall** (www.otw.org.uk) – From 8 years old
 - **Wood Larks** (www.woodlarks.org.uk) – From 10 years old
 - **Camp Whizzkidz** (www.whizz-kidz.org.uk) – From 12 years old
- **Specialist holiday companies for people with disabilities** – You can find many organisations which provide holidays for people with disabilities on Google
- **Skiing holidays** – If you want to take your child skiing, Disability Snowsport UK (www.disabilitysnowsport.org.uk), Crystal Ski (www.crystalski.co.uk), Ski 2 Freedom (www.ski2freedom.com) and similar organisations can help you

Your family can have wonderful holidays together

You can contact specialist holiday companies and charities which have the facilities and services your family needs to have a wonderful holiday together.



Grant-giving and wish-granting organisations

Across the UK, there are charities which specialise in granting wishes to children who have serious illnesses and their families.

They provide opportunities for having fun and creating special memories. Some charities will also provide equipment, such as garden play equipment, sensory equipment or household items.

If you would like to apply for a grant for your child, these wish granting charities might be able to help:

Starlight Children's Foundation

www.starlight.org.uk

Make a Wish

www.make-a-wish.org.uk

When You Wish Upon A Star

www.whenyouwishuponastar.org.uk

Rays of Sunshine Children's Charity

www.raysofsunshine.org.uk

Promise Dreams

www.promisedreams.co.uk

Family Fund

www.familyfund.org.uk

Child Flight

www.childflight.co.uk

Dreams and Wishes

www.dreamsandwishescharity.org

Dreams Come True

www.dreamscometrue.uk.com

Online gaming

Many children, teenagers and adults with DMD are enthusiastic online gamers.

They can make friends, play games and have fun on an equal basis with their peers. Some also enjoy designing and building games of their own.



Fundraising together

Many families of children with DMD fundraise for themselves.

They often use GoFundMe or JustGiving to raise money for equipment (e.g. off-road wheelchairs) or adaptations to their house.

Friends and the local community are usually happy to help. Some families also contact their local newspaper about their fundraiser and have received generous donations from readers. But not all families are comfortable appearing in the press.

Fundraising for medical research

We know that the people who are most passionate about raising money to find treatments and a cure for DMD are the ones who live with it every day.

Many DMD families raise money for Duchenne UK to fund medical research. Together, we have raised millions of pounds which we are investing in research right now to bring treatments and a cure to this generation of children

When you feel ready to start thinking about fundraising, you can find information on the Duchenne UK website at: www.duchenneuk.org/how-you-can-help

For when you are ready start thinking about fundraising

We are raising money for this generation of children



