Learn to Live with Neuromuscular Disorders (NMD):

A Message for Parents and Caregivers

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Introduction

No matter how strong you are, it is tremendously difficult to deal with the grief, stress and fear when your child is diagnosed with neuromuscular disorder (NMD). It is normal to feel helpless and lost. In times of hardship, trust that you can find the courage to face the challenges ahead, and remember to ask for help whenever you need it! The purpose of this pamphlet is to help you to get through this difficult time. Bear in mind that everyone develops different coping methods at his/her own pace. Once you are able to gather the strength to confront and deal with these strong emotions, you will have made a huge step forward.

Content

① What is NMD?

One of the key steps in coping is to better understand about Neuromuscular disorders (NMD). NMD is a genetic disorder that affects parts of the neuromuscular system (i.e. muscles and nerves). The mutations that lead to the disorder can be inherited, or it can be the result of a spontaneous genetic mutation. Although a parent can be a carrier of the mutations, this does not necessarily mean that their child will be affected. The probability of having an affected child varies from 25% to 50%, depending on the type of inheritance.

The symptoms of NMD include, but are not limited to, paralysis, weakness, pain, muscle spasms, stiffness, gait disturbance, abnormal coordination, dizziness and syncope. Special care might be needed for some patients who have issues on their cardiovascular and respiratory systems.

Learning about NMD would equip you with the ability to communicate with your family, friends, teachers, doctors and other healthcare professionals about the disease condition, as well as the difficulties you face especially when caring for your child. As family and friends start to understand more about NMD, they could then lend you helping hands in the best ways possible.

If you have any further questions about Neuromuscular disorders, please kindly refer to the references at the end of this booklet, or consult your Paediatrician for more information.

② A NMD Parent's Sharing

6-year-old Tung Tung has Duchenne Muscular Dystrophy (DMD) When he first started to walk at the age of one, he was constantly tripping and falling. We are honored that Tung Tung's mother kindly agreed to share how she copes with the hardships when caring for Tung Tung.

1. **How did you feel when Tung Tung was diagnosed with Duchenne Muscular Dystrophy?**

   "When we were waiting for the laboratory test results of DMD, I felt lonely and I did not want others to know about the test, as I was worried that Tung Tung would be stigmatized and discriminated. Once I found out that my son had DMD, I felt sad, stressed and helpless. Especially

given that there was no obvious physical difference between Tung Tung and other healthy children, I felt like nobody would understand my worries, and I was unable to share with others my concerns. I kept blaming myself for not knowing about the positive family DMD history from my grandmother's side. It was all too overwhelming. Depression hit me; I heard voices speaking to me, and I also developed suicidal thoughts. Luckily, with the kind helping hands from supportive and caring friends, teachers and healthcare professionals, I was able to slowly pick myself up again and start afresh."

2. **How did you cope after learning Tung Tung's diagnosis?**

   "It took me almost a year to acknowledge his diagnosis. My husband and I cried together after learning about it. Nonetheless, Tung Tung was sweet and smart enough to comfort us, and he told us not to cry. In order to find out more about DMD and the best ways to care for Tung Tung, I started to read about the disorder online to learn more information.

I still recall that I had a difficult time in choosing a suitable kindergarten for Tung Tung, Tung Tung's doctors kindly reached out and helped us to secure a spot in a kindergarten that was well-equipped to support his physical needs; and Social Workers and Nurses also cared a lot about me, and listened to me when I felt stressed. I really appreciated the Dietician's tips on the importance of maintaining a balanced diet, as well as the Physiotherapists' recommended stretching exercises to enhance my son's flexibility. Gradually, with the help of my Clinical Psychologist, I started to share my worries and concerns with others. I learned that one needs to show a lot of love and encouragement when caring for a child. Tung Tung hated putting on his orthopaedic braces, so his teacher suggested putting on cute, colourful stickers on his braces. Now he is always very excited to put them on! In

addition, I was also very lucky to have met a group of mothers at Tung Tung’s kindergarten, who show immense support for one another.

In fact, it is very important to leave yourself some personal time. When I feel or upset, I take a break to relax and rest. For example, I love jogging or playing squash. Also, I learned to actively ask for help when I need it. Throughout the years, I have been trying hard to cope with all the ups and downs in life, by taking things one step at a time.”

3. **What are the major challenges in caring for Tung Tung?**

“The hardest parts are persuading Tung Tung to exercise; making sure that he is putting on his orthopedic braces and taking his steroid regularly, and ensuring that he has a balanced diet. It takes a lot of patience to encourage and care for him. Tung Tung recently graduated from kindergarten. Instead of sending him to a mainstream primary school, we decided to send Tung Tung to a special school for the physically-handicapped, where they can provide special care such as wheelchair pick-up services, in case Tung Tung will need it in the near future. All we want is to have a supportive learning environment for him to grow and learn.”

4. **How do you balance your relationship with your husband and other family members?**

“I was very worried and nervous when I found out that Tung Tung had DMD. My husband complained that I was worrying too much and being over-protective of Tung Tung. My husband initially had a hard time processing Tung Tung’s DMD diagnosis, so we were both emotionally and physically drained. Slowly, we worked our way through communication. We would share our worries honestly and be

there for each other. As Tung Tung's grandmother tends to worry a lot about him as well, my husband and I try to pay extra attention to her feelings and comfort her when she stresses out about our son."

5. **How is Tung Tung doing now ?**

"It is hard for Tung Tung to walk up the stairs now, and he needs to use his hands to support himself when standing up from the ground. A few weeks ago, Tung Tung and his friend were running on the playground with their hands held tight. Tung Tung could not run as quickly as his friend, so he tripped and fell. It broke my heart to see him hurt both of his knees, but I didn't tell them off, I simply wanted him to enjoy school life. During his kindergarten graduation ceremony rehearsal, Tung Tung's legs tired out easily. Although he was frustrated, he kept at it and gave his best performance. Steroids have made Tung Tung's condition better, but it has also resulted in more hair growing on his back, and we have to pay extra attention on his diet. Tung Tung knows that he is less physically capable when compared to others, but he does not fully understand the disorder. We are planning to explain his condition to him in greater detail in the near future."

6. Do you have a word of encouragement for other parents?

“It is important to face your problems with a positive attitude, and try to find the best way to help your child. Crying alone will not help to cure his/her diseases. All NMD children require a lot of support and care from their parents and family, so be there for them. Take all the time you need to make adjustments slowly. Try to share your thoughts and worries with other patients’ parents, they will listen, understand, and open up to you, offering you a helping hand.

③ Acknowledging your Emotions and Feelings

At first, the diagnosis may be a shock to both the patient and the parents.. You may feel numb at first; and you may then feel like your whole world is crumbling down, or that things feel surreal. You may feel the urge to isolate yourself from everyone, as strong emotions such as fear, guilt, hurt, depression and helplessness emerge. Eventually, these feelings could develop into strong individual responses, such as:

- Appearing strong. You may feel that it is the duty of parents to appear strong by concealing their unresolved negative emotions, such as resentment and fear, deep in their hearts.

- Denial. You may fall into a period of looking for other opinions to deny the reality.

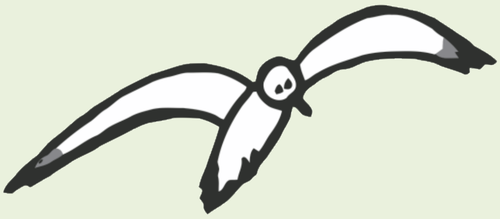
- Anger. You may become angry at yourself, doctors, family, friends and even your children.
- Depression. You could collapse into a deep depression, feeling a strong sense of helplessness and hopelessness for the future.

Meanwhile, you may also experience some physiological responses:

- Headache
- Insomnia
- Feeling of generalized weakness
- Nausea
- Shortness of breath
- Digestive problems
- Fatigue and lack of energy
- Dreaming a lot and feeling like you haven’t slept all night

When there is a loss in our lives, we experience grief. Grief is a natural and necessary process that your mind and body needs in order to cope with the pain. Acknowledge that all emotions are transient. They arise, stay for a while and then disappear. They can come and go to you, like waves in the sea, cresting and receding.

Grief becomes a problem only when you let it take over and ruin your life. Psychiatrist Dr Elisabeth Kübler-Ross has described 5 stages of grief that people tend to go through as they come to terms with pain and stress.



① Denial – Refuse to accept the fact of diagnosis

② Bargaining – Attempt to postpone the inevitable

③ Anger – Blame due to the encounter

④ Depression – Feel helpless and fatigue to life

⑤ Acceptance – Embrace and accept the reality

The truth can be hard to accept, but not acknowledging the truth, blaming yourself and others, will only prolong your grief and withhold yourself from the natural process of acceptance and coping.

The best thing you can do is to allow yourself to experience the different stages of grief as they arise. Accept what is happening, and ask for help when you need it.

④ Reaching Out and Finding Strength in Your Support Network

You might not be a talkative person, but expressing your struggles to your partner, family, and friends can be an important and liberating step towards healing. If you need to cry, let it out. If you only need your beloved ones to be there next to you, tell them. Find the most comfortable way for you to share your feelings.

Some may appear strong on the outside, hoping that it will make their family and close friends worry less, even though they may be agonising inside. Imagine pumping up a balloon. It can only be filled with so much air only. If you keep adding more air without letting any out, the balloon will eventually burst. Real strength is derived from your ability to cope with your challenges in life.

On the contrary, sharing your worries and thoughts to your close friends and family, will allow you to slowly begin to understand and break down your fears and insecurities. It will guide you to tackle challenges and problems with positivity.

If you find it uncomfortable to talk about your feelings, you could try writing. Writing can often be a powerful medium for addressing and coping with your grief. As you write, you may start to clear up your mind and find order in what initially felt like a sea of chaotic feelings. It also helps to make sense of your reactions and reflect on how they may be affecting your life. It is difficult to deal with all the stress of caring for a NMD child alone. You might even feel like the whole world is on your shoulders sometimes. Call your beloved ones for help. Let them know what you need from them. They care about you, and they will always be there

for you. Remember that no one expects you to give up on everything that you once had to care for your child.

If you are not sure about who to include in your support network, you can make list of contacts whom you believe you can rely on for help, such as your parents, siblings, friends or even trusted doctors and therapists. They can be the pillars of strength to support you through hard times.

I would like to express by:

☐ Talking face-to-face ☐ Phone ☐ Social network

☐ Letter ☐ Diary/Writing ☐ Others: _______________

Those I can trust & share my struggles with:

1. _____________________ 2. _____________________

3. _____________________ 4. _____________________

5.______________________6______________________.

⑤Building Healthy Relationships

Even your closest friends and family may not fully understand what you are going through as a parent caring for a NMD child. This, unfortunately, could create frictions between you and your support network; you might even feel isolated. Some may pity you for what you are experiencing, but are unable to give you the positive support that you need; some may choose to ignore the significance of NMD, deny the diagnosis, or even insist that your child has been misdiagnosed. Some may even blame it on your child or your family for putting you through such tough times.. All these comments and reactions could stress you out with multiple levels of negativity. Thus, it is vital to educate those around you on NMD, let them know what NMD means to you

and your child, how you see the disorder, and how you want them to see it.

Your spouse

Spousal relationship can often be jeopardised during the transition. Your priorities will change. Many of your daily routines and responsibilities will undergo significant transformations.

First of all, both of you will be grieving in your own ways. Misinterpreting your partner’s reactions can lead you into unnecessary fights, sadness and pain. Hence, it is very important to be open and honest when communicating with each other, this could help avoid misunderstanding, and to better support one another.

Furthermore, you may find it extremely stressful, both physically and mentally, with the numerous changes to your daily life. On top of your regular schedules, extra time will be taken up to care for your child such as going through daily therapies and consultations. Your free time will become scarce and limited. It is, therefore, essential for the both of you to share the new responsibilities to avoid one partner from being over-burdened.. For instance, while it may have been the case that only one of you were solely in charge of household chores and childcare before, you could now both take turns in bringing the child to different treatment sessions. This could significantly reduce any unfair strains that one of you might be experiencing, and it could also bring you two closer together by better understanding what you both need for support.

Meanwhile, strains in your relationship may not always be due to conflicts, but instead you lack time for one another. Foster your relationship by scheduling alone time for you and your partner, to treat yourselves, and to relax together.

Your children

NMD children can grief and be upset about their own conditions too. . They may ask questions that you do not know the answer to. Their moods may also fluctuate from depression, guilt and anger. As a parent, you can start preparing yourself for these questions and situations ahead of time so that you will have the strength to properly react to your child’s grief. Turn to positive sources like doctors, therapists, and parents of other affected children to find out the most suitable and effective strategies to help your child.

Do not be evasive with your child. Address his/her concerns positively and let your child know why he/she needs special care from you. Also, if your child has siblings, educate them all on their individual differences. Explain why your child needs special care from you to avoid the other siblings from feeling left out. Once they understand the importance of their brother's / sister's needs, invite them to help care for your ailing child. This could help bring them closer together as brothers and sisters.

Although your child is living with NMD, this does not mean that you should treat them differently when it comes to rewards, punishments and disciplines. Keep it fair to everyone. If you give your affected child no responsibilities, even in things that could be within their abilities, he/she may feel inadequate. Moreover, games and physical activity reduce the rate of muscle

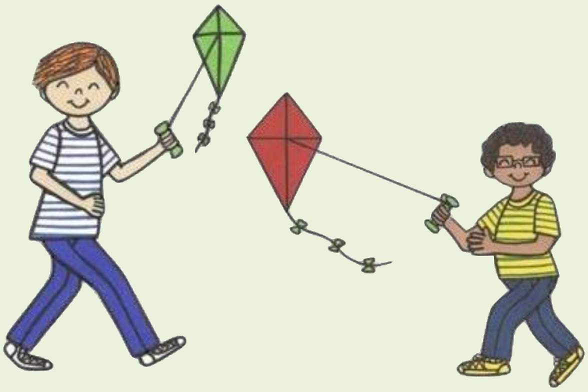
degeneration significantly, so try your best to let you affected child to enjoy his/her favourite activities.

You may be wondering, when would be the best time to let your child know about their diagnosis? And how should you tell him/her? You could tell your child during the consultation with your Paediatrician; or you could bring it up during a regular conversation at home. But remember, do it when your child is calm. The following table provides with a few suggestions on how much details that you could share with your child, depending on his/her age:

Age	Suggestions
2 years old 	➢ Encourage your child to explore the world by trying out different things. Try not to limit any activities as long as they are safe and within the reach of his/her physical abilities. ➢ Show your support by telling them to never give up. Let them know you will always be there.
3-4 years old 	➢ Briefly explain to them what NMD is; let them know how different they are from other children. But also remind them that they are just as capable as their peers in many ways. ➢ Keep encouraging them to try new things in life, and try not to be over-protective. ➢ Discuss with them on the difficulties that they face in their daily lives. Guide them with suggestions and possible solutions, as appropriate.

5-12 years old 	➢ Tell them what NMD is and what symptoms they might find. You could also encourage them to look up for more information in their own time for better understanding. ➢ Let them understand that there is so much more than just NMD in their lives. The key is to keep moving forward with a positive attitude, and to never give up. ➢ Encourage them to develop their own interests, and to pursue their goals and dreams in life!

Resentment may build up if you force sibling relationships on your children. It may take time for them to get along. It is usually through struggles and fights that siblings learn to care for each other and embrace their differences. Gradually, they will develop a loving relationship at their own pace.



⑥ Moving Forward with Positivity

The final and most important step to positive coping is toacknowledge that changes are constantly taking place in life, and are inevitable. Thus, the key to life is to take on a positive attitude as you face new obstacles and challenges. Do notgive up on your favourite hobbies or anything that makes you happy. You are a parent of a child with NMD, but you also deserve to be happy. You are definitely worthy of your hopes and dreams. Continue your interests and work towards your goals in life, take good care of your physical and mental well-being. As you adopt an active and healthy lifestyle with positivity, you will spread the love and energy that your child and family need to power forward!

The activities and interests I would like to keep pursuing

1. ____
2. ____
3. ____

As the old saying goes, time is the best medicine. We should not expect ourselves to deal with all the grief, changes, and difficulties right away. With time and understanding, you will become a stronger person. You will be able to handle challenges ahead. Helping hands are all around you. Have faith and be brave, trust that you can get through these difficult times for brighter, clearer days ahead.

For more information,

please contact the Clinical Psychology Department

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References

- Queen Mary Hospital and The Duchess of Kent Children's Hospital at Sandy Bay, Hong Kong - Paediatric Neuromuscular Diagnostic and Management Program http://paed.hku.hk/website/nmd/index.html
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