DMD 'on the ball' supported by 9
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Introduction

When you were younger it was the adults around you who made decisions on your behalf but now, like many young people, you are growing up and discovering that your goals and ideas are important and there are things you may want to change. Perhaps you are feeling more confident and capable about making up your own mind about life.

Maybe you want to have more fun, gain new freedoms and responsibilities, or you may want to be more involved in decisions about your health. Independence often begins with people taking on this sort of responsibility. You may also be exploring ‘real life’ thoughts and feelings that you haven’t yet shared with anyone else.

All this can be exciting, but sometimes a ‘bad patch’ can leave you feeling a bit uncertain. Talking with other people about how you feel can help. By sharing your thoughts you will find there is a lot of information available and loads of great ideas to help you solve any problems or worries you might have.

This booklet will start you off. So, if you are between 11 and 14 years old and have Duchenne muscular dystrophy (DMD), then this is for you.

If you want further information about DMD call the Muscular Dystrophy Campaign Information Officers on 020 7720 8055, or email info@muscular-dystrophy.org, or you could speak to your Family Care Officer in confidence.
You will have been told that you have something called ‘Duchenne muscular dystrophy’ (DMD). Put simply this means that you have a problem with your muscles, which makes them weak. This is not your fault and you did not catch it like a cold. It occurs because of a ‘mistake’ in a piece of genetic code called the dystrophin gene, which is located deep inside your cells. Every single person in the world is made up of millions of cells and inside each cell is a very important structure called the nucleus. The nucleus houses our genetic material on little sausage shaped structures called chromosomes. Most of your cells have 46 chromosomes (23 pairs), on each of these chromosomes lie several hundreds genes each with a specific function. Our genes make us what we are – the way we look and, yes, sometimes even the way we behave!

Now for some really complicated science: each chromosome is made up of genetic material called DNA (deoxyribonucleic acid). DNA is also known as a double helix and looks like a curling, twisting ladder. It is composed of nucleotides consisting of three parts, a base (there is a choice of four types, A, C, G or T), a type of sugar (not the kind you put in your tea, but believe it or not a related form!), and phosphate. It is the order of these nucleotides that makes us who we are and unique from everyone else. This DNA is tightly packed into the chromosomes, and although the cell is less than 1mm across, the DNA inside it is about 2m long. Some very clever people have worked out the following fact: as we are made up of millions of cells, if you took the DNA out of all your cells and lined it up end to end, it would be long enough to reach the moon and back thousands of times.

The weakness in your muscles is caused by a ‘mistake’ in a gene called dystrophin. Our genes contain special instructions to make proteins, and the dystrophin gene makes dystrophin protein. There are many proteins in our body and each one has a different function; for example, transport proteins are involved in transporting substances around the body and between cells. One of the functions of the dystrophin protein is to give strength to muscle cells; when it is absent the muscle cells are weakened and cannot perform properly.

You may think that this all sounds a bit complicated and scary, but you are not alone; many people have ‘mistakes’ in their genes and these can cause all sorts of problems. Some are similar to yours and others are very different. It’s a bit like building a house – there are thousands of things that can go wrong. Sometimes the mistake won’t be noticeable (one brick slightly longer than the others, for example) but sometimes it might make a huge difference (like a hole in the roof).

In order to help your muscles stay as strong as possible it is really, really important that you stay as healthy as you can.

Many scientists around the world are working to find a cure or therapy for DMD. First, they needed to find the fault that causes the problem. This was no small task given the amount of genetic information they had to study but they did it! Now they are working out why it causes the problems you experience. Scientists are also looking at ways to treat and ultimately fix the problem and this is the focus of much research world-wide.
Two scientists who are funded by the Muscular Dystrophy Campaign to work on DMD are Professor Kay Davies and Professor Diana Watt

Professor Kay Davies is now one of the world’s top md researchers, but until the early 1980s she was working on another genetic condition called cystic fibrosis. It was then that the Muscular Dystrophy Campaign approached Kay and talked to her about DMD. She realised that if she worked on DMD she could develop methods which would also be helpful to her cystic fibrosis research. After meeting some boys with DMD Kay began her new research and has not looked back.

Kay is developing a novel way to replace dystrophin with another very similar muscle protein called utrophin. This is a really exciting idea because if you have DMD the gene that makes utrophin is undamaged. Unfortunately, the utrophin gene is programmed to switch off (i.e. stop making utrophin) very early in our lives. Undaunted, Kay has developed a special mouse model called the mdx mouse – this is a real mouse that also has a mistake in its dystrophin gene. She hopes that by studying it she will find chemical compounds that might be able to control the amount of utrophin which is produced in the body.

Professor Diana Watt

“I first became interested in muscular dystrophy when I took up a post at Charing Cross Medical School in 1977. At that time there was some scepticism (disbelief) about the ability of muscle to regenerate (make new cells) but there was some evidence that it could. The group I joined at Charing Cross had the idea that if muscle could regenerate then perhaps it could incorporate normal muscle cells when it was regenerating. If that was the case, dystrophic muscle (the damaged muscle) might be able to incorporate normal muscle cells (without the mistake in the dystrophin gene) into its fibres and this could help to rebuild the affected muscle fibres. At this time the gene involved in DMD was not known and also dystrophin, the missing protein had not been discovered.”

“We set about finding out if normal muscle cells could be integrated into dystrophic muscle. It was not until 1994 – many years later – that I discovered that a cell in the skin could become a muscle cell and help rebuild damaged muscle fibres.”

“I think the future for research is very good indeed. Way back in 1977 not a great deal was known but, in the time I have been researching, the genes responsible for many muscle conditions have been discovered and this helps us understand more about muscles and how to correct them when they go wrong. There are now several lines of research going on which could produce really important results in developing ways of preventing the dystrophic muscle becoming so badly affected.”

“Science, however, always takes a long time as we must be absolutely certain of what we are doing and make sure we don’t create more problems than already exist. Our work therefore has to be thoroughly researched and tested.”
Experts say that we all need to eat healthily from a wide range of foods but...

**Too much of a ‘good thing’?**

Foods high in sugar and fat are very tasty, and because they are tasty it is easy to eat a lot of them! But they are loaded with calories. If you eat more calories than you burn up, the result is too much fat. So as well as cutting down on obvious high calorie foods watch out for those hidden calories too.

### Burgers = amount of fat

- Packet crisps
- Small bag peanuts
- Doughnut
- Two sausages
- Cornish pasty
- Bar of chocolate
- Fish & chips

**Remember** – All oils and fats (including butter and ordinary margarine) have the same amount of calories.

### Cakes = amount of sugar

- Boiled sweet
- Tablespoon tomato sauce
- Thick & creamy yoghurt
- Bar of chocolate
- Can of cola
- Slice of cake
How good is your diet?
We all know that what we eat affects our health, but do we manage to eat healthily? Try this short quiz to see how you score:

1. What do you usually start the day with?
   a. Sugar coated cereal
   b. Toast with lashings of butter or margarine and some other spread
   c. Nothing much
   d. Cereal with very little or no sugar
   e. Toast with a thin scraping of butter or margarine

2. Do you use…?
   a. Skimmed milk
   b. Semi skimmed milk
   c. Whole milk (full fat)

3. At lunchtime do you…?
   a. Have a packed lunch with just sandwiches and fruit
   b. Have a packed lunch as above with crisps and/or a biscuit (including chocolate!)
   c. Just have a drink and crisps and/or a biscuit

4. What is the drink you have most often?
   a. Ordinary fizzy drinks/squash
   b. Diet or low calorie fizzy drinks/squash
   c. Milk
   d. Water
   e. Pure fruit juice

5. If you are hungry between meals what are you most likely to reach for?
   a. Biscuits
   b. Fruit
   c. Sweets
   d. Bread/toast
   e. Crisps

Vitamin in the spotlight
Vitamin A is essential for good eyesight and healthy skin (it is used as a medicine for some people with acne). You can get Vitamin A from the orange substance, called beta-carotene, which is in fruit & vegetables.

There are many more vitamins and minerals – C, E, B, calcium and iron – and you can find out about them and about the food we eat from books and the Internet. Try ‘How does my diet affect me’ by Patsy Westcott for starters!
Fast food = healthy food?

Many people would think that the above equation doesn’t balance, but you can eat healthy food while on the move as long as you choose carefully.

Baguettes/pitta breads/wraps with salad/cold meat/egg/tinned tuna (in brine or water). If you can’t do without mayo use a low calorie version but remember that even these are high in calories so only have a teaspoon. You can also use pickles and relish to add lots of flavour.

Jacket potatoes with baked beans/low fat cheese/prawns/tuna in brine. But don’t add butter or margarine, although reduced fat margarine would be OK.

Pizza. At home get pizza bases and make your own pizzas rather than getting the high fat, high calorie take-away types. If you are eating out try to choose the pizza with less cheese and more veggies.

Beans on toast is a nutritious quick snack that is high in fibre; this means it will keep you feeling fuller for longer than other snacks.

Sausage & mash – but make the mashed potato with skimmed milk and don’t add butter or margarine. Try to have only one or two thin sausages and cut them into halves or thirds, then stick them into the pile of mash so they look like more sausages! Reduced fat sausages can taste good too.

Pasta with sauce is very popular and can be quite low in calories. Just boil the pasta then add a ready-made tomato based sauce with tinned sweet corn and/or tuna. To spic it up add a little chilli sauce or a small amount of chopped salami. Try to avoid the creamy, cheesy sauces.

Chilli con carne is very good especially when made with lean meat and plenty of vegetables, kidney beans and tomato puree. Try it with cumin as well as chilli powder.

Soups can be really tasty and fill you up without too many calories. There are many ready-made ones, both fresh and tinned, which are low fat. Look at the nutrition label and choose vegetable soups or reduced fat soups and again try to avoid the creamy ones.

Even a ‘fry up’ needn’t be a plate of grease! Try thick sliced potatoes fried (the thicker the slices the less fat they absorb). Grill a lean rasher of bacon with tomatoes and mushrooms and serve with baked beans and lightly buttered toast. (A good tip – you mustn’t be able to see your teeth marks in the butter!)

Lower calorie puds

Any type of fresh fruit or frozen or tinned fruits in their own juice (not syrup)
Diet yoghurts (low calorie)
Sugar free jellies

Fibre – why eat it?

Fibre means you feel fuller for longer and it keeps the bowel healthy. The bowel is a large muscle which must be given work to do to keep functioning properly and the fibre in your diet is what this muscle uses to exercise! As the fibre is pushed through the bowel by the muscle, it acts like a sponge and absorbs water. That’s why it’s important to drink plenty of fluids (but make sure it’s water or a low calorie drink because sweet fizzy drinks will add calories to your diet). You can increase your fibre by eating high fibre breakfast cereals, wholemeal bread and beans and pulses (try lentils and chickpeas) and of course fruit and vegetables.

HOT TIP
Pack a punch with your packed lunch!

Lunch is an important meal. If you don’t refuel in the middle of the day you could well end up over-eating after school because you’re so hungry. By choosing a balance of foods you can feel full without having too many calories.

Sandwich fillings

Grated cheese – use only a little, a slice of lean meat, tinned fish (in brine or water), prawns. Always have a vegetable in the sandwich, for example, grated carrot, sliced peppers, cherry tomatoes, cress, sprouted alfalfa, shredded Chinese leaves, baby spinach as well as all the traditional salad vegetables. If you need mayonnaise choose the low calorie variety and only one teaspoon per sandwich. Take a bag of raw chopped veg such as carrot, celery, peppers, cucumber, and baby sweet corn.

Have lots of fruit such as grapes, peeled citrus fruit and apples, pears and banana are excellent. To help you get your five a day you could make up a big mixed fruit salad, but remember to squeeze a little lemon juice over it to prevent it going brown.

If you like yoghurts get the diet types or at least the low fat ones. And for something else sweet try a fruit bun or scone with a little jam (but not butter) or have a few dried apricots or raisins.

Try to have crisps only a couple of times a week and at other times try some home made popcorn (you can buy the kernels at most supermarkets) and pop them yourself. Pour a little vegetable oil in a large saucepan and when the oil is hot sprinkle a single layer of kernels on the bottom. Put the lid on the pan and as soon as you hear the first ‘pop’ turn down the heat and shake the pan occasionally until the popping has died down. Add salt to taste and eat.

Finally, drink water or low calorie squash and unsweetened fruit juices.

Quiz answers, what did you score?

Scores for questions

1. a.2 b.1 c.1 d.3 e.3 2. a.3 b.2 c.1 3. a.3 b.2 c.1
4. a.1 b.3 c.2 d.4 e.2 5. a.1 b.3 c.1 d.2 e.1

Scores

15+ excellent 10-15 very good
under 10 improvements are definitely needed to this diet!

Remember that eating healthily doesn’t mean you have to eat boring food. You can eat the things you like, just don’t eat too much of them and balance them out with healthy foods. Why not experiment with unfamiliar foods and new recipes? A little imagination can make a big difference to what’s on your plate.
Feeling real good

Feeling shy?
Want to be more confident?
Just be yourself!

This is good advice but what if you don’t feel confident enough to ‘be yourself’. You may compare yourself unfavourably to other people like celebrities or even your friends.

The reason the world is such an interesting place to live in is because everybody has different skills, abilities and ideas to contribute.

Self-esteem is about feeling good about yourself and who you are. And it matters. It matters a lot!

Self-esteem means you can enjoy being with a group of people you don’t know and feel comfortable, it allows you to have a laugh with your friends – even if you’re the butt of the joke – and people with a high level of self-esteem are usually more assertive too (that is, letting other people know what you want and what your opinions are without going into a strop!).

So, how do you get ‘self-esteem’? Well, by being both proud of who you are and valuing yourself. One way you can begin to build your self-esteem is by developing your own style and looks.

Everyone wants to look good (even though some people don’t appear to care – think ‘grunge’). Film stars and models always seem to look good but remember it’s their job to look great, they have lots of people to help them and they get paid tons of cash. The rest of us have to be realistic about our appearance and there are some things we can’t change. Remember the song – ‘Nobody’s Perfect’. So, be positive and concentrate on the good things about yourself. You may have a nice smile, great teeth or great hair gel (= great hair).
about yourself

Get the books

If you need any help, a book written just for boys called *Style Blitz* by Helen Thomas has ideas and tips on looking your best. It gives you tips on getting rid of acne (as if!) and hints about shaving and personal hygiene. Anita Naik has also written a very helpful book called *Self Esteem* (it’s part of the Wise Guides series). Try your local library for a copy.

One way of dealing with those people who want to ‘pat you on the head’ or ignore you (sometimes called the ‘does he take sugar’ syndrome, because they don’t think disabled people can speak for themselves) is to be direct, and speak up with a suitable comment. To be able to do this takes confidence, so practice in the safety of your own room, well away from others and you’ll soon gain the confidence to make yourself heard.
Begin by writing down the problem or difficulty.
Break down the ‘problem’ into achievable chunks or bites by asking yourself:
- When is it due in?
- What help do I need?
- Where can I get help?
- Where do I want to do the work – at home, at school at a friend’s house?
- How much time should I give to each part?
- Keep checking that you are on course and, if necessary, make changes.

One solution is to be positive and imagine it not as a ‘problem’, but a ‘challenge’. Once you start thinking in this way many of your fears will go away and you will give yourself a genuine ‘can-do attitude.’ You might find it hard to think like this and try to deal with your worries yourself, but this might not be such a good idea. It can be really helpful to talk to someone else, perhaps a friend, a teacher, an older brother or sister or even your parents. All these people can offer support and understanding. Talk, talk and talk is the best advice around.

If you really feel that you can’t talk about a fear that you have, then apply the strategy that we talked about in the bullying section. You can raise the problem (oops, challenge) as a topic that you have recently read about in a book or seen on a television show, and then you can openly discuss it with someone you trust who can help. Talking will make it easier to give the challenge a sense of proportion. Not being perfect at something is not a disaster and very likely your worries are needless.

When trying something new, like learning a foreign language or taking up a new hobby, you may quickly feel frustrated and drop it because your skills don’t match up to expectations. In these situations your confidence can take a knock, but remember to have that ‘can-do attitude’ and set yourself realistic weekly or monthly targets.

Think about what you want to achieve. An example could be a school project about a subject you know nothing about. Your ultimate goal is to submit a thoroughly researched and well-written project to your tutor and be confident of receiving a good mark.

Get the idea?
By applying this method to difficult or complex matters you will have a sense of purpose, know where you are and therefore stand a good chance of succeeding.

A HOT TIP
A useful saying that can remind you how to use this technique, is ‘if you want to eat an elephant – eat it a bit at a time!’ It just means, break down a problem and tackle it bit by bit.

Why worry?

Everybody feels a little scared at some point in their lives – it could be while wheelchair abseiling over a cliff or when watching a horror film! But you can also feel nervous about a big event, where you may be the centre of attention. Perhaps you have to give a speech at school or deal with a difficult situation and you may feel that if you are not absolutely perfect, people will make fun of you.

A tip for those who find that their short-term memory is not too great: use ‘post it’ notes around your room. Stick them on your schoolbooks. Stick them on the mirror. It’s a great idea to help jog your memory.

A tip for those who want to find out more about stress try ‘Stress – find out how to handle it’, (part of the Wise Guides Series) by Anita Naik £3.99. Struggling with feelings – try www.youngminds.org.uk
Bullying stresses people out and can spoil lives. Even the milder forms of bullying such as name-calling or excluding people from groups can be very upsetting. It is a deliberate and hurtful act that could happen to the same person over and over again. Sometimes it happens to people who are a bit different, but most of the time there is no obvious reason. The best thing to do in all cases of bullying is to take rapid action but, unfortunately, people who are being bullied are often reluctant to talk about what is happening to them and they may even keep it a secret. Why? Well, people often feel upset or ashamed to admit that they have been singled out for this type of treatment. They often think ‘Why me? What have I done, what have I said? Perhaps they (the bullies) took something I said the wrong way.’

If you know someone who is having a bad time because of a bully, can you do anything about it? If you have experienced bullying yourself you probably know what action to take. But if the person being bullied doesn’t want to talk about it, what can you do?

One strategy is to read a book or story about bullying or perhaps you can remember a TV show about this kind of hurt. You can then bring up the subject by talking about the book or programme – how good the story was, the difficulties the main characters faced, their dilemmas and the choices they made. You can also use this strategy to talk to your parents, teachers and friends about other embarrassing, complex, personal subjects. Remember that bullying is nothing to feel ashamed about and schools take it very seriously.

www.pupiline.com offers tips and do’s and don’ts on dealing with bullies.

www.getconnected.org.uk is a free helpline to help you find the best help whatever the problem.

Bullying

You have probably heard about Childline. It offers a 24-hour helpline for children and young people. Call 0800 1111 (if you find it difficult to use an ordinary phone you can use textphone on 0800 400 222) and talk to them about any problem, including bullying. The call is confidential (no-one else will know) and they will offer advice and help. www.childline.org.uk

Kidscape is a charity that works to keep kids safe. It takes bullying very seriously and offers help to any kids being bullied. Its helpline is 020 7730 3300 www.kidscape.org.uk.

Two recent novels that feature bullies and bullying are ‘Traitor’ by Pete Johnson and ‘4 days ’till Friday’ by Pat Moon. Your local or school library will probably have copies.

There are other people who can help:

The site www.bullying.co.uk offers advice and strategies on dealing with bullies (including text message bullying). It also gives advice to parents and schools and has information about the current legal position on bullying.
Meeting Ben and Mark

When I first met Ben and Mark they were both hard at work on the football field, employing all their skills and expertise in setting traps for defenders, avoiding tackles from centre forwards and putting pressure on the midfield. Yes, I had discovered ‘Pro-evolution Soccer’. It’s a game that requires inspiration and a ‘no surrender’ attitude.

Not surprisingly, football is 14-year-old Ben Parkin’s greatest love and he and his pal, Mark, are just mad about it.

When it comes to supporting a team, Ben reckons you can forget about the ‘Reds’ the ‘Blues’ and ‘the Clarets’. For Ben, the green and yellow of ‘the Canaries’ (Norwich City) are the only colours ever allowed near his room.

I asked Ben more about his favourite activity.

“My number one Norwich City player is Iwan Roberts, who used to play for Wolves. In fact when I saw Wolves play Norwich I thought then he was a great player, even though he was playing for the opposite side. Mark Rivers, the right midfielder is pretty good too, so is Paul McVey.”

Ben is optimistic about the present season: “We’re in a fairly good position and hopefully will get into the Premiership within the next few years.”

Mark agrees, although he has a guilty secret: “I also support Chelsea, but I am a Norwich fan at heart.”
Ben laughs, “those are the best words you have ever spoken and I’ll never let you forget them.”

Because Ben uses a power chair full-time and likes to get out and about, he needs places to be easily accessible. He wants to attend all the important footie matches, travel to pop concerts at Wembley, go bowling with his mates, shop in town and enjoy holidays abroad. Ben has strong views about being free to go where he pleases.

“A couple of years ago I went to Florida with the Make a Wish Foundation. I swam with dolphins, visited Disney World and Universal Studios (where he spotted a Canaries fan – “the shirt gave him away”). I was really impressed by the Americans’ matter of fact attitude to disability. Access was amazing; I could do the same as everybody else. As soon as I arrived at Orlando Airport my chair was waiting for me, very different from what happens at Gatwick.

“Because being independent is important, my wheelchair is vital to me. I use it everyday to travel to and from school on my own; it means mum doesn’t have to get the car out to take me. I was the first person using a power chair to go to my school, so they had to put in lifts and ramps, delayed action doors and an accessible loo complete with a hoist (although I don’t think much about where they put the loo!). All this took time but it means that other kids, like me, can go there rather than to special schools which may be far away from their homes.

Ben and Mark’s fave sites are www.canaries.co.uk and www.miniclip.com
And the BBC footie site www.bbc.com/football
And there are even better reasons for doing exercises. But first, you need to make sure that you are doing the right type of exercise.

Q. If my muscles are weak why can’t I use weights to make them stronger?
A. Because the membrane of the muscle is fragile, overworking the muscle by lifting heavy weights could damage it. But there are other active exercises, which you can do yourself, that are good for you.

Q. Why does my physio want me to have hydrotherapy when I just think it’s a pain getting undressed and dressed again!!
A. Hydrotherapy is probably the best way to exercise if you have a muscle condition. The warm water supports your body and relaxes your muscles, which makes stretching exercises much easier. The best thing about hydro though is being able to move much more freely than you usually can and it’s really good fun!
Q. What is the point of stretching exercises?

Stretching exercises are perhaps the most important exercises for all ages. Anybody who sits in the same position all the time will get stiff and uncomfortable. If you have a muscle condition, the stiffness can become permanent if the muscles and joints are not moved and stretched. Physios and doctors call this stiffness a ‘contracture’. Knees, for example, normally bend right back so that the calf and the back of the thigh meet and they can also straighten up. In muscular dystrophy, there may not be a problem in bending the knee, but sitting in a chair all the time can make it difficult to straighten up. Joints that don’t have a ‘full range of movement’ can get achy and it’s sometimes difficult to find a comfy position in bed. So best to just get on and do those stretching exercises!!!

Q. What about my hands and arms?

A. Hands and arms need to be stretched too. Playing computer games is very important to most boys whether they have muscular dystrophy or not. Keep your fingers flexible, especially if you play for long periods of time. Ask your physio what you can do (yes – it’s more stretches!).

Q. What about my feet?

A. Looking good is important to many young people. If contractures of the feet and ankle develop, this might make it difficult to wear the sort of trainers or shoes you prefer. Wearing splints every day will keep your feet in the right position so that you can look good (and yes, there are stretches which will help too!). The posture of the upper leg is very important when looking at your foot posture. If your legs flop apart, your feet turn on to their sides (try it!).
I have a powered chair. At first I was a bit anxious about it but now I am really good at using it. Of course, I’ve had to practice a lot.

A caller to the Muscular Dystrophy Campaign Information Line.

Do you need help?

Whizz Kidz has a new scheme for people under 18 who use powered mobility called ‘Keep on Moving’. It helps you to learn how to use your chair safely and with confidence as well as get new skills and become more independent. There are different levels within the scheme for different ages. Look at its website Keeponmoving@whizz-kidz.org.uk or phone 0207 233 6600 or e-mail info@whizz-kidz.org.uk

The Association of Wheelchair Children also provides advice about wheelchairs. It teaches skills that help develop confidence when using a powered or manual chair. Contact the Association at www.wheelchairchildren.org.uk

If you are 13+ and interested in getting involved with Whizz Kidz then it is interested in getting involved with you. It has set up a Board (a group of people who meet regularly with a common purpose) to give young people a say in the organisation. Whizz Kidz wants the Board to let them know what it is doing right and how it could improve in the future. Even better than telling someone else what to do, Board members have also taken part in television and radio interviews, had stories published in national magazines and newspapers, attended functions and media events and generally had a good time.

wheelchairs

Always make sure that your legs are properly supported by the wheelchair.

You wouldn’t dream of wearing clothes that didn’t fit you properly so why should you put up with a wheelchair that doesn’t fit? Having the right wheelchair makes you feel more comfy and looks better.

Are you comfortable in your chair or are you leaning over to one side? If you think your chair is too wide ask your physiotherapist or occupational therapist for advice.

Do you bend forwards to get your arms comfortably on the armrests? Do the armrests dig in? Ask your physio to check the height of the armrests and ask about adjustable ones.

Do you feel tired and want to lie down when you come in from school? Do you find it hard work keeping your head up? Find out about Tilt in Space wheelchairs from your physio or occupational therapist and see if they might be suitable for you.
Almost everyone has an opinion about using animals in medical research and sometimes feelings can run high. There are loads of arguments for and against the use of animals. Some people believe using animals is necessary because of the vital and special role they can play in medical research.

Scientists say that almost every medical breakthrough we have – for example, the polio vaccine, insulin to treat diabetes and even organ transplants – all owe something to the use of animals in research. Without animals, scientists believe, it would be highly unlikely that any of this life saving work would have succeeded.

People who are against the use of animals in research are called anti-vivisectionists. They think it should be banned completely and claim that continuing to use animals is pointless. Anti-vivisectionists say people and animals are biologically very different and that there are better methods of research such as using specially developed computer models. Biologists would agree with this to a point but they argue that the similarities between humans and animals are greater than the differences and that these differences are always taken into account.

**Animals in research**

So what does the future hold for animals in medical research?

Well, something called the ‘three R’s’ of animal research is becoming more viable (possible) every year. These are a set of guidelines which scientists work to:

- _R_ is for replacement. Using alternative methods such as tissue cultures.
- _R_ is for reduction. Using fewer animals.
- _R_ is for refinement. Improving procedures when carrying out research.

The good news is that scientists, such as those researchers working on muscular dystrophy already use tissue cultured cells, donated muscle biopsy material and computer models. They only use animals (usually mice) when there are no alternatives and then under extremely strict guidelines. Because most researchers stick to the strict rules laid down by the Government, the Home Office recently reported that fewer animals than ever are being used in medical research.

One mouse, which is of special interest to the Muscular Dystrophy Campaign, is the famous ‘mdx’ mouse that has been written about so often in _Target md_ (the bi-monthly magazine published by the MDC). This mouse has a naturally occurring genetic and biochemical abnormality, similar to that found in DMD, and has enabled researchers to explore potential treatments, which could not be accurately modeled in a laboratory.

Want to know more about animals in research? There are loads of websites; check out the following for different views:

- The BBC: [www.bbc.co.uk/science/hotopics/animalexperiments](http://www.bbc.co.uk/science/hotopics/animalexperiments)
- [www.kids4research.org](http://www.kids4research.org)
- [www.simr.org.uk](http://www.simr.org.uk)
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