

Praful



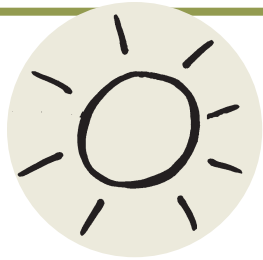
Praful is 17 years old. He is a very content young man - comfortable in his own skin. He is ambitious and lives life to the full. He has a very clear sense of direction and knows what he wants to achieve in life. Praful has Muscular Dystrophy (MD), which is caused by faults in his genes (the units of inheritance that parents pass on to their children) and results in progressive muscle weakness because muscle cells break down and are gradually lost. He has the Duchenne type of Muscular Dystrophy, which only affects boys.

Praful embraces new experiences and exciting activities. He enjoys being with his friends in different settings; at school and at the hospice where his friends have the same illness as he has. It really helps to talk to them and share experiences as they really understand and often face similar challenges in life. He is very close friends with two boys called Harry and Mike.

Praful lives at home with his parents and younger brother, RJ, who helps with his care. He cannot walk any more and uses an electric wheelchair. As his muscles have weakened in his body, he needs some help with all areas of daily living. Praful feels his friends at school do not always understand how he feels.

He has regular respite at a children's hospice, where he has supported independent breaks from his family, along with other young men with Muscular Dystrophy or life limited illnesses. He really looks forward to his hospice sleepovers/holidays He is doing A-levels and attends six form at school and wants to go to university. He loves computers and would like to study ICT.

What does a good day and a bad day look like for me?



I wake up really late, about 11.00am on a respite stay at the hospice and have a bath in the big bath with the lights on in the water and music blasting out loud in the bathroom – especially Katie Perry and Cold Play.

Eat a full cooked breakfast with my friends, Mike and Harry.

Out for the afternoon on a trip – driving racing cars is my favourite.

Back to the hospice – MacDonalDs for tea – Big Mac and chips in front of a film to chill out, then loud music and a chat, or playing computer games with the lads – Mike and Harry.

Order a pizza in about midnight and have a beer

Bed really late, about 3.00am!



I wake up and feel stiff and uncomfortable.

I have to get up and dressed, have a quick breakfast with help from my brother and be ready for school transport at 7.30am (too early for me as mornings are not my best time of day).

I have my worst teacher first lesson, who puts me in a bad mood– maths! I do not find A-level maths easy and he does not wait for those who cannot keep up.

Lunch at school is disgusting – stew and semolina.

It is pouring with rain and I get soaked every time I have to go outside. I can't run like everyone else. I can only go at the top speed of my wheelchair.

Transport home is really slow because of heavy traffic.

Mum has had a bad day at work and dinner is late.

I have homework to do and then have to get straight into bed early, with help from my brother RJ who is going out for the evening after helping me.

Making changes to my life - my action plan

Who	Will do what	By when
<p>School transport services. My driver is called Steve Jones.</p>	<p>Provide flexible transport, going to school and getting home. Instead of going to school at the same time each morning I go in at different times to suit my day at school. Sometimes my lessons start after break or later on in the day. I come home when I am ready and do not have to hang around at school until 3.00pm.</p>	<p>By the end of November 2010.</p>
<p>Head of Family support team Jane Clarke, Hospice respite support services.</p>	<p>Provide me with 3 or 4 weeks of additional respite support. This would give me an opportunity to experience supported independent living in respite care during holidays away from my family. I would like to start by going food shopping and by learning to cook some meals so that I can feed myself independently.</p>	<p>Agree and book dates in January 2011 for an additional week of respite each academic term in February, May and October 2010.</p>
<p>Connexions/careers support services. My Personal Advisor (PA) is Chris Smart.</p>	<p>I am involved with all transition planning and have time booked with a careers expert, personal advisor (PA) to help me consider the courses I can do at university and careers that I can achieve and enjoy. I spend time with my PA and get information about which universities can accommodate me so that I can enjoy university life, study and socialise. This will help me to make informed choices</p>	<p>This Autumn term by the end of November 2010.</p>

What is working and not working in my life and what do I want to change?



College is great and I am enjoying my A-levels. I am very interested in computers and ICT and would like to work with and design computer games in the future.

I really benefit from my respite stays as I see my friends with Muscular Dystrophy who are facing similar challenges in life. I also gain some independence by spending time away from my family. I am able to go out on trips for example I go sailing and I visit places that I would not normally be able to get to, like London.

Enjoying a rest and recharging our batteries when Praful has 2 weeks residential respite stay at the hospice.

me

Planning where I can go to continue studying after I leave school is difficult. I would like to find a college or university that I can go to and read computer technology. I would like to gain the skills to work with computer game design and development. The university I attend will need to be close enough for me to live at home or I will need to make arrangements for supported independent living so that I receive the care I need.

I have no help at present with how to find a university/ college that runs a course that I would like to do and that could accommodate me. I don't know how to find accommodation with the support I require.

family

We only receive 2 weeks respite care a year.

We do not find it easy to get away on holiday because Praful needs so much help. We and Praful would find some regular term time local respite provision helpful, 1 or 2 weeks a term, where Praful can stay independently with the care he needs.

If I could, I would...

Drive a very fast sports car.

Go sailing every week.

Find a faster wheelchair.

Spend more time with my mates, Harry and Mike, in respite - it's like a big sleepover and I have fun. I also know my family have a good rest whilst I am away.

Try and talk my parents into letting me live on my own with other support, not from them.

Go to college to study, I would like to design computer games.

Go abroad for a holiday... or maybe just go on holiday full stop.

Try and do more for myself.

Eat a Big Mac at MacDonaldis at least once a week.

Who would I like to do what towards the end of my life?

Who would you like to:

Say goodbye to before you die?

My brother, my parents, my friends at school, my friends from the hospice, especially Mike and Harry, my grandmother.

Be there in your last moments?

Just my brother, my Mum and Dad.

Organise your funeral?

I want my parents to sort out my funeral. They are good at organising things.

Invite to your funeral?

I would like everyone who knows me to be invited along.

Read at your funeral?

I would really like my brother to read at the funeral. He could maybe write me one of his funny poems and tell some jokes.

Organise a memorial or celebration of your life?

I would want a celebration of my life, a party type thing, I do not want people to be all miserable.

Write your obituary?

My parents would be the best people to write about my life, with help from my brother, as they know all the important things I would want everyone to remember.

Other things I would like to ask people to do/ help with:

I would like to record a CD with me singing with help from my music therapist so that it can be played to all my family and friends from me, as a way of saying goodbye. This would be something my family could keep as a memory.