

Ability House  
15a Tottenham Lane  
London

Sally asked me to put together this scrapbook to help illustrate some of my experiences as a disabled young person trying to get the help I need. Thanks to Action For Kids, I hope I am nearly there now - but I still need your help.

Dear Sally

My name is Emma. I've heard that you may be able to help me so I wanted to explain how much a new wheelchair would benefit me.

I have sustained spasms all over my body, caused by generalised Dystonia. A spasm down the right side of my trunk causes severe pulling over to the right, and for this I need invasive seating to enable me to sit up straight without too much pain or pulling. I am also hoping the seating will help prevent some of the severe spasm attacks I experience when my head, neck and arm are pulled about uncontrollably.

The wheelchair I need also requires an F16 on it. This is a small, portable power pack that can be added or removed from the chair. Having something like this that can be placed in the boot of a car along with the chair would give me so much freedom.

Even simple things like going to the supermarket will be much less of an ordeal. I will be in less pain while I am out, I will be able to stay out longer and if you're kind enough to grant me an F16 I will have a new level of independence without needing someone with me all the time.

The chance to sit up comfortably and be in less pain, not to mention the independence, it just fills me with excitement! With the summer coming up, I am looking forward to getting out and having some fun!

If you were able to help, I would be more grateful than I could ever put into words.

Regards  
Emma



Sally Bishop  
Action For Kids  
Ability House  
15a Tottenham Lane  
London  
N8 9DJ

Dear Mrs Bishop,

Re: Emma

I am a Care Manager/Social Worker based with The Disability Services in Cambridge. I am currently working with Emma, providing services within her own home, in order that she can remain independent within her local community.

I am writing to offer my professional opinion regarding her current mobility needs. In short, I would be really grateful if you could give Emma your kind consideration for some funding for a new manual wheelchair with a specialised seating system that would make a huge improvement to her physical well-being.

Emma has been diagnosed with generalised Dystonia. This causes constant spasms in her trunk, which pull her over to her right side. Her left hand has a sustained spasm, and she also has spasms in her left shoulder, which affect her neck, head and face.

All of this means that she very desperately needs a combination of highly specialised mobility aids in order to be able to lead an active, independent life.



This is the F16 Powerpack that will help me get more mobile. It will mean I can have a powered wheelchair when I need it - and more independence.

This is the special seating that will help me sit up straight at last. It's called Foam Karve and is the same as Formula 1 racing cars use.



88 South Street • Stanground  
Peterborough • PE2 8EZ England  
TEL: (01733) 342242 or 344930  
Fax: (01733) 312489

Thank you for your time on Thursday and I hope you're well. Please find hereunder our quotation for the lightweight chair as requested:

1 x Sunrise Medical RXS Manual Wheelchair as per our assessment	£1034.00
1 x Sunrise Medical F16 Power pack to fit RXS	£2435.00
<b>TOTAL</b>	<b>£3469.00</b>

This quote doesn't even include the cost of the Foam Karve seating, which I have applied for separately. The total cost of everything I need is a whopping £7,707.

Please be aware that this is highly specialist equipment so approximate delivery time if required would be 4 weeks.



Dear Friend,

Four years ago I got ill with a virus that no one has been able to identify. It struck me hard with severe pain and other debilitating symptoms. Over the years we've realised that my illness is progressive – meaning it's getting worse. We now know I'm suffering from something called Dystonia.

I have very severe and prolonged muscle spasms. For instance, the fingers on my left hand are completely curled up and have been for two years – that is a prolonged muscle spasm. I also have a sustained spasm down my right side, which causes me to pull over to the right. On top of that, I get severe spasm attacks, which pull my head, neck and arms about all over the place.

Bear in mind that I was 17 when all this started. I was so happy, learning how to drive, having a normal life. In the beginning, I struggled, but now I can see new opportunities for my future.

At the moment I do volunteer work for the council. I sit on a panel that audits any new building in Cambridge, where I live, making sure they're fully wheelchair accessible. I'd love to do some more volunteer work – maybe with the Citizens' Advice Bureau. Then maybe university at some point. There are so many courses I'd like to do – maybe some kind of occupational therapy. There are opportunities open to me and I've always said that once my pain is more manageable I'd like to get a job and get on with life.

But first of all there are a lot of things I need to sort out. I need a manual wheelchair and the most important part of that is the seating. The seating I'm hoping to get is called Foam Karve and it's amazing. They literally carve foam

to your exact shape. I really struggle to stay upright at the moment but with Foam Karve I'll be bolt upright, which is a really exciting thought.

Of course, I'll be really blessed and grateful to get any help at all but other seating will never match up to what Foam Karve would do for me. I'd live but it would mean that I'd be in more pain when I went out. It would make life that bit harder. At the moment it's really difficult to go out and keep happy and smiling because after about 25 minutes I'm in quite a lot of pain and I can't move around properly. Being able to sit up straight - and having the pain relieved - is going to help everything. There'll be no stopping me.

That's why I'm so excited that Action For Kids are trying to help me get the equipment I need. They're one of the few children's charity that can help me because they help young people up to the age of 26. Most other children's charities cut off at 18 years old so it can be very tricky. There are a lot of disability charities but none that I have come across who are as helpful as Action For Kids.

But it's actually people like you who make them so generous. It's your support that lets them help children and young people like me. I would be so unbelievably grateful if you could help them to help me get the future I'm dreaming of.

Yours truly

Emma