

Feedback on Posture and Mobility Services  
provided by Opcare



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## Report Details

This is a detailed report outlining the findings of the work completed by Healthwatch Calderdale and Kirklees regarding Posture and Mobility Services (Opcare), the organisation commissioned by the NHS to provide wheelchair services.

## Background

In July 2016 Healthwatch was contacted by a parent of a wheelchair user, who had made a complaint to Opcare on behalf of her daughter. She was concerned that there were other parents experiencing similar problems so Healthwatch signposted her to the review section of its website and encouraged her to leave feedback on the service. She did this and also shared the information with other parents, carers and service users, who also completed online reviews.

In October 2016, Healthwatch was approached by organisations working with parents and carers of children with disabilities who wanted their service users to have opportunity to give feedback on Opcare. Healthwatch also was contacted by individuals via its signposting and NHS Complaints Advocacy services, who wanted to talk about their experience of Opcare's services. This feedback prompted Healthwatch to engage with people further on this subject.

## Approach

During March and April 2017, staff from Healthwatch arranged to meet support groups for parents and carers of children and young people with disabilities. Healthwatch facilitated focus groups to give people the opportunity to have their say on their experience of using Opcare's services. People were asked a range of questions, specifically:

- What are the top five gaps in the service?
- What is working well?
- What is not working well?
- What could be improved?

An online survey was also created so that people could still give feedback if they couldn't attend the focus groups or if they wanted to remain anonymous. The survey asked the same questions as the focus groups but also had 'star rating' sections for covering staff attitude, confidence in technical staff and access to premises.

Healthwatch also created case studies from some of the more detailed stories we heard from people and these have been included at the end of this report.

In total we engaged with 91 parents/carers of services users and service users using the methods listed in the table below:

Method of engagement	Number of participants
Survey	27
Focus groups	38
Online reviews	22
Telephone/email	4

*Table 1: Methods of engagement detailing participant numbers*

Additionally, we spoke to 4 professionals who either work directly with people who use wheelchairs or support those who do.

## What we found:

Some people had positive things to say about Opcare's services, however most comments were about difficulties people were experiencing. We asked people to identify five key service gaps, which are listed below.

### 5 key service gaps

<b>1</b>	<p><b>Opcare does not routinely offer assessments to children and young people.</b></p> <p>Children are not being regularly assessed and reviewed to identify whether their wheelchair meets their size and needs. The responsibility lies with parents and carers to get in touch with Opcare if they feel their child needs to be assessed and only then are they put on a waiting list to be seen. However, many parents/carers are not aware that it is their responsibility to contact Opcare for a review. This means that problems can be missed and, because of the lengthy waiting times, children and young people have no option but to use unsuitable wheelchairs, often resulting in pain, discomfort, poor posture and unnecessary injury.</p>
<b>2</b>	<p><b>There are unacceptably long waiting times for service users to be assessed.</b></p> <p>Parents, carers and service users told us about being put on waiting lists for assessment, leaving them waiting months for an appointment and then being put on a further 2 or 3 waiting lists for measuring and fitting appointments. This means that some people are waiting over 12 months for a suitable wheelchair.</p>
<b>3</b>	<p><b>The majority of people we spoke to are unhappy with the repairs service.</b></p> <p>People spoke of their concern regarding length of time it takes for repairs to be carried out and also the fact that wheelchairs are being repaired, in excess of their life span, instead of being replaced.</p>

<b>4</b>	<p><b>Communication: People want to be provided with clear, accurate information and they want their voice to be heard</b></p> <p>Whether people are waiting for repair, assessment, or for delivery of a new wheelchair they want to be kept informed with accurate facts. People often feel that they have to chase up appointments, phone calls and visits and struggle to get the right information about how long they will have to wait.</p> <p>Additionally, people feel Opcare doesn't take their concerns seriously and even when an ill-fitting wheelchair is having a serious impact on the health and wellbeing of the service user, and health professionals support these concerns, people don't feel they are listened to.</p>
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<b>5</b>	<p><b>Equipment not fit for purpose</b></p> <p>Parents, carers and service users told us that equipment is often not fit for purpose as the wheelchairs and seating systems provided often are not suitable for the environments in which the service user, their family and carers wish to use them. The equipment is therefore not promoting independence and inclusion.</p> <p>People were also very concerned that many of the wheelchairs provided were providing inadequate posture support. We also heard of instances where poorly fitting wheelchairs and seating systems were causing necessary injuries such as pressure marks. We also heard of cases where unsuitable equipment had had more serious consequences such as admission to hospital (Accident &amp; Emergency and Intensive Care) and surgery.</p> <p>There were also concerns raised by many people that wheelchairs were being repaired rather than replaced due to financial constraints.</p>
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### What is working well?

**A small number of people were impressed with the speed and efficiency of the repairs service and technical staff.**

The main themes and comments are shown below:

“...major repairs carried out quickly”

“...new part fitted immediately”

“technical staff really great and knowledgeable. Visited child at school so I didn't have to go to them”

“Engineers are sent out quickly; they know staff and service users at the Trust” (Next Step Trust)

“They are usually prompt and come when they say”

“If technical staff come out to repair one child’s wheelchair (at school), they will also look at other children’s wheelchairs” (without appointment)

### Some people seem happy with face-to-face interactions with Opcare staff

“Staff at Posture and Mobility Services are friendly and courteous”

“When I attended a meeting at their office in Elland, the staff were really friendly and polite”

“I feel Opcare provide a good service and all the individuals I have had contact with during the repairing process have been helpful and courteous”

“Great staff and all of them compassionate and caring and able to deliver outstanding customer service in a timely manner”

### A few people are happy with the process for getting a new wheelchair and with the wheelchair they receive

“We got the basic manual wheelchair delivered at home after a GP referral”

“Straightforward process for obtaining an electric and manual wheelchair”

“The new (seating) mould is fantastic. It’s the best she has ever had”

“Had quite a long wait to get a wheelchair but once it had been done, someone from Opcare gave me a call to check whether everything was OK. That was good”

We also heard about instances where people had initially received a poor service but after contacting Opcare, and sometimes complaining, they then received an excellent service. This shows there are occasions when Opcare has listened to their service users and has responded to their concerns.

“Success story. After bringing our situation to attention of my local Member of Parliament, I now have an appointment for my daughter for a new wheelchair the after waiting for four years”.

## What is not working well?

### No regular reviews/assessments for growing children

Parents/carers tell us they are incredibly frustrated by the fact that there is no regular, routine assessment in place for their child to ensure that the wheelchair they are using is suitable for their size and needs (see case studies 1 and 2).

Members of staff at a school and day care centre spoke about how they have felt obliged to take on the role of ‘reviewer’ themselves, recording any wheelchair issues which they, staff, service users or parents/carers experience, and speaking to Opcare on behalf of the people they work with.

### Poor communication

People told us how they struggle to get information from Opcare and wanted it to be much clearer about when service users could expect their matter to be dealt with:

“Very little communication between Opcare and parents”

“No progress reports for waiting lists”

Additionally, people complained that making phone calls was time consuming and yielded no reward. The quote below provides an example of how one parent wanted Opcare to communicate:

“...give accurate information/timescale about when a problem can be assessed. Keep individuals informed if an agreed timescale cannot be kept”

People told us that conversations on the telephone are often very difficult; they feel Opcare staff are defensive, unhelpful and sometimes rude. Staff were described as uncompassionate and lacking in empathy. People struggle to get the information they need which leaves them feeling frustrated and at a loss as to what to do next:

“(I) was told wheelchair would be ready pre-Christmas. I chased them mid-February - spoke to someone who answered the phone who was completely unhelpful and uninterested. It turned out the chair hadn’t been ordered...couldn’t tell me why, or when it would be available”

Some people feel their views are just not listened to and even when health professionals and consultants have written supportive letters to Opcare, people feel this has made no difference at all to how Opcare dealt with their issues:

“Communication not good at all, after a lengthy conversation of issues, Opcare was not taking on board anything I said”

“Not listening to other professionals’ suggestions”

This has sometimes resulted in formal complaints being made which people told us are not always handled well.

People also mentioned that there was poor communication between Opcare and other NHS health professionals involved with the service users:

“No communication between occupational therapists, physiotherapists and Opcare”

Parents/carers and service users also felt that reception staff were not knowledgeable about the service so were unable to help them with their enquiries.

“Reception staff are not knowledgeable about the service”

Parents and carers would like to be involved in the service user group which Opcare has set up but don’t feel it’s accessible for all; the meetings are always in Elland in the evening and this makes attendance difficult for parents and carers who live in North Kirklees who have young children and rely on public transport.

Several people also informed Healthwatch that they had no idea where Opcare’s premises were.

## Waiting times

**People spoke of the frustration they felt during long periods when they were on a waiting list at various points when being assessed for a new wheelchair.**

“How would they feel if the chair they rely on all day has become unsafe or uncomfortable and they have to spend all day in it”



“My daughter has been on this waiting list for well over a year”

“...waiting time for appointments 18 months”

“When you do make an appointment, there is an exceptionally long wait - by the time you make the appointment there is already a problem with the chair”

“Waiting lists are now more than 12 months for special seating clinics which is much worse than in the old service where 3 clinics a month were held for this seating and has been reduced to 1 per month”

“My daughter was poorly seated for well over 2 years....Despite lots of phone calls, emails, complaints to the service this was not acknowledged and we were constantly told that she was on a waiting list”

“I moved to the area and attempted to get an appointment with Opcare in February of 2015, it took until November 2015 to get me an appointment with the service and this was (with) a lot of pestering and badgering as it seems they kept losing my case”

One parent spoke frankly about the despair she felt throughout a very lengthy wait for assessment and how she feels about having to put in other requests for assessment in the future.

“This is a service I will need to use for the foreseeable future and I am absolutely dreading having to start the process all over again when my child outgrows her current chair”

## Repairs

One member of staff in a school told us how some of the technician's turn up with hardly any tools and say they've only have 2 weeks training.

“I could see him scratching his head thinking how do I fix this bit back on. It's not their fault - they're not given the right training and tools to do the job. Also, they don't carry spare parts so often the technician has to take photographs of the wheelchair repair that needs doing, then go back to the office to order the part. This delays things further and some children have to miss school because their chair is unsafe to travel in. It's disheartening”

People were also unhappy about the wait time for repairs and that an appointment time isn't always given.

“The waiting time for repairs is poor, not able to give a time means our adults have to wait in all day”

“I booked an appointment for a repair twice but nobody turned up, nobody got in touch to cancel. I then have to spend time making more phone calls to chase things up”

“Sometimes the time it takes to assess an issue and then resolve an issue/complete a repair can be very frustrating”

“(We need) quicker repair times and a time when they are due to call out”

The length of time it takes to get a repair can be substantial and this can have a huge impact on children and adults because they can't take part in their normal day-to-day activities; we were told about children having to miss school because their wheelchair isn't safe to travel in and about adults who are stuck at home waiting for a repair to take place

Wheelchairs being repaired/upgraded when they need replacing, rendering them unsafe, uncomfortable and failing to provide adequate posture support was also a theme that was frequently mentioned. One parent said that her son of twelve had his wheelchair frame for six years. Although the wheelchair chair is due to be updated, she has been informed by Opcare he will have to keep his current frame. This parent was worried that this solution will not be suitable as her child will be entering adolescence and growing, whilst using a wheelchair frame that he has had since he was a young child. Another adult service user spoke of how she had made Opcare aware of problems with her seating and its negative impact on her posture only to be given numerous different cushions over a two-year period before Opcare decided her current wheelchair could not provide the seating system she requires (see case study 3).

### Equipment not fit for purpose

People raised concerns that service users' needs change so much between assessment and receiving their new or adjusted chair, that their new or adjusted wheelchair then doesn't fit properly. Delays in adjustments and repairs also meant that wheelchairs were not fit for purpose. We were told of service users who were uncomfortable in their wheelchairs, children who were unable to concentrate at school due to this discomfort and of an adult who felt her ability to work was being compromised by her poor wheelchair seating.

“Chair not fitting correctly when received due to waiting time of three months”

“A new chair arrived (after 10 months) and straight away we noticed that it looked too small and that the back was tilted...we raised a concern but were told it was fine...no one came to look (at the wheelchair). The physiotherapist and occupational therapist also say the chair is not right. We are now waiting for an appointment to reassess. Our child has now been in a chair that is not right for 18 months”

One parent commented that the only purpose her child’s wheelchair fulfilled was for safe transport on the school bus and the school day. The child could not use his wheelchair for family days out.

A significant number of people also mentioned that in many cases the wheelchairs provided did not provide adequate posture support for people with complex needs who require specialist wheelchair seating. These people usually require help with posture throughout the day and night (24-hour postural management) so it is essential that their wheelchairs, alternative seating and night positioning provide this support. People spoke of the discomfort caused by poor posture from sitting in unsupportive wheelchairs.

“For the last few years her posture has been at risk due to her wheelchair having poor footplates and a seating system that was not ideal. This as you know puts her independence and functioning at risk which is crucial to her whole mental health, physical health and well-being”

“A wheelchair with no support was presented to me. My son needs specialist seating, not a standard wheelchair...my son has three crush fractures on his spine, plus curvature of the spine. He needs support (in his wheelchair) but they can’t see that as professionals.”

“My daughter’s legs are too long for the footplate position and there is no further room to lower it, the sides are too narrow for her frame”.

“On a young person who requires 24-hour support with postural care this was a damaging seating system”.

One parent said that her son’s current poor wheelchair posture was limiting his movement. She said when her son was supported and restrained in his wheelchair, the range of movement in his arms and hands is greatly increased and his head control significantly improved.

Another parent told us that the consequences of her son having to sit in a wheelchair that did not provide adequate posture support was having serious health implications:

“Wheelchair is compromising health, scoliosis is becoming fixed, surgery is now needed. Abdominal pain, struggling with bowels”

### Funding and Commissioning Issues

Parents/carers and service users told Healthwatch that they had been informed by Opcare that it was not possible for the service to provide them with new wheelchairs due to “funding”, “no money” or “budgets”. One service user stated:

“Every experience I had had is they Opcare just do not want to give people a wheelchair or seating options as it is money”

People said that there were also unsure as to whether Opcare offered the NHS voucher scheme, which gives service users a wider selection of wheelchairs from which to choose. Others felt that where the service user needed a specialist wheelchair that was not routinely provided by the NHS, there was a lack of support for Individual Funding Requests for funding from a Clinical Commissioning Group, which can only be submitted with clinician support.

Opcare has informed many of the parents we spoke to that it is struggling to meet demand. Specifically, it has stated that volumes are 50% above the indication in the tender.

Opcare is receiving more referrals per month (in one case more than double) than it is commissioned to process. This leaves the organisation in an untenable situation

and unless commissioners urgently review the contract they have with Opcare the difficulties which service users are experiencing will continue.

Many of the people were spoke to understand that this is a problem for Opcare and would like to see this addressed.

“Opcare is struggling with their contract and they are not sufficiently funded to meet patient needs. This is having a great impact on the holistic health and wellbeing of patients!”

One parent stated that she would like “more funding to be made available to Opcare from the Clinical Commissioning Group”.

### Accessibility of clinics

Staff and service users in North Kirklees have been made aware that Opcare is paying to have a room at Eddercliffe Health Centre in Cleckheaton but it never uses this. Having a clinic based here would make the service far more accessible to people in North Kirklees, rather than having to travel to Elland.

When the Clinical Commissioning Group announced that Opcare would be delivering wheelchair services it stated that there would be community-based clinics, close to patients’ home and in North Kirklees this would be the Eddercliffe Centre.

### Order delays

People mentioned that Opcare staff often told them that items were are on order when they were not. They said they would rather be told the truth, even if the waiting time was going to be lengthy.

“...had an assessment for a wheelchair and was told it would take six months to arrive. After 6 months we rang and the wheelchair had never been ordered”

### Choice of wheelchair

We also spoke to several people whose perception was there were “limited options for wheelchairs” and “limited choices for specialist seating”:

“Choice of wheelchairs (not the cheapest, what is best fitted for child)”

## Parent/Carer and Service User Ratings of Opcare

Parents/carers and service users were invited to give Opcare a star rating to reflect their experience of its overall service as well as for components of its service. A high numerical rating indicated a good service experience, whilst a low score showed a poor service encounter.

Results from our online reviews and survey indicate that parents/carers and service users collectively gave Opcare a star rating of 2.1 out of 5.

The following ratings were obtained from our online survey

	<b>Average rating (out of a maximum of 5 stars)</b>
Access to premises	3.4
Communication	2.3
Staff attitude	3.2
Confidence in technical staff	3.1
Confidence in admin support	2.9
Helpfulness	2.7
Flexibility of appointments	2.3
Waiting time	2.0

*Table 2: Ratings of components of Opcare service*

## Opcare's Perspective

At the time of writing this report, we asked Opcare to tell us what it thought about the feedback we'd received about its services so that we could include its perspective, but unfortunately nobody from Opcare was available to comment. At the end of August 2017, we were told that Opcare and the Clinical Commissioning Group were producing a statement to summarise the current position, which would include information relating to a contract extension and some additional, non-recurrent funding for Opcare's wheelchair services. This statement will sit alongside our report once it is available.

## Next Steps

Healthwatch is supporting Opcare to undertake further stakeholder engagement. This will ensure that the voices of all Opcare stakeholders are heard. Healthwatch will continue to discuss with the Clinical Commissioning Group and Opcare how the service can be improved.



## **How can the process of getting a new wheelchair be made easier for a child with a severe physical disability?**

Ellie is 12 years old and has needed to use a wheelchair from a very young age. The last wheelchair she had became unfit for purpose because she had outgrown it. The process for acquiring a new wheelchair was long and challenging for her mum, Michelle, and Ellie's health suffered so much whilst waiting that Michelle felt forced to pay privately to get a new wheelchair for Ellie.

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Ellie is 12 year old and has severe, complex and life-limiting disabilities. She has needed to use a wheelchair all her life and ever since she was born her mum, Michelle, has been consistently told how important it is to ensure her seating position is correct because, if not, this can have a serious, damaging impact on her health and wellbeing. Ellie has nowhere else to sit; if she's not in her wheelchair she is in bed so it's crucially important that her wheelchair is comfortable, safe and meets all her physical needs.

In May 2016, Michelle could see that Ellie was not sitting comfortably in her wheelchair because she'd had a significant growth spurt and had gained 10kg in 6 months. Michelle contacted Opcare (the company who provide wheelchairs) to arrange for an assessment with a view to obtaining a new wheelchair, but she was told that the assessment probably wouldn't take place before the end of 2016 because they still have people on the waiting list from the previous year.

Weeks went by and Michelle still hadn't received an appointment. Ellie was really starting to struggle with being incorrectly positioned as this made her extremely uncomfortable and caused a significant amount of pain. She is non-verbal but was sometimes screaming in pain when seated in her wheelchair. Michelle was regularly phoning Opcare to emphasise how urgent the matter was. Things deteriorated even further and Ellie required lots of extra care to manage her worsening health because a lot of the time she was slumped over to one side, putting increased pressure on her lungs. She suffered repeated chest infections and eventually ended up in intensive care because of complications arising from this. Michelle obtained letters from Ellie's physiotherapist, occupational therapist, the hospice consultant and her paediatric and orthopaedic consultant; all the letters stressed how important it was for Ellie to have a wheelchair which met her needs but the letters don't appear to have made any difference.

In desperation, Michelle scraped together £3,000 to buy a wheelchair from a private company and she received the new wheelchair within 1 month of Ellie being assessed. As soon as Ellie was sat correctly her health improved; she needed less suctioning of fluid from her chest because she was in the correct position so fluid wasn't settling in her chest anymore and she hasn't experienced any more chest infections since having the new wheelchair.

Opcare eventually offered an appointment for an assessment in November 2016; after this appointment there would have been 2 or 3 further appointments necessary for moulding of the wheelchair seat and, at each stage, people are placed on a waiting list.

Michelle says that in the past, children have been routinely been given regular review appointments to assess whether their wheelchair is still suitable for their age, size and needs. Children grow regularly and can have significant growth spurts and it seems obvious that their wheelchair needs would need to be regularly reviewed.

Michelle has made a complaint to the Clinical Commissioning Group but this hasn't progressed so she talked to Healthwatch about her experience. Healthwatch are speaking to Opcare and the Clinical Commissioning Group to understand where the problems are in the system and how things can be improved so that no child with a disability has to experience such a distressing, lengthy process to obtain a new wheelchair.



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**Obtaining a new wheelchair for a child with a disability shouldn't be this difficult**

Olivia is 14 and because of her disability she has had to use a wheelchair all her life. When she needed a new wheelchair because she'd outgrown the one she had she was put on a waiting list and eventually had an assessment but the wrong wheelchair was ordered which led to an even longer wait.

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Olivia is 14 and has a physical disability which means she has to use a wheelchair. Her mum, Ann-Marie, noticed that she'd outgrown the one she was currently using and so contacted Opcare (the company who provide wheelchairs). She was placed on a waiting list and it took months for an assessment to take place. When the assessment was complete, it was agreed that a moulded seat needed to be ordered.

Following the assessment, an occupational therapist who didn't know Olivia, decided that a moulded seat wasn't required but nobody informed Ann-Marie that this decision had been taken.

When Ann-Marie was informed that the new wheelchair had arrived it soon became apparent that it was the wrong one. This error meant the wheelchair couldn't be used as all, which wasted £4,000 and caused a further delay for Olivia because she had to have a new seat moulded. By this time, Olivia had pressure sores from spending long periods of time in a wheelchair which was too small.

Ann-Marie made a complaint and contacted her local MP for support. Opcare provided a new wheelchair within 4 weeks which Ann-Marie was pleased about but she is concerned about the potential damage caused by Olivia being seated in an awkward position for such a long period of time. Ann-Marie says x-rays have shown a significant change in the curve of Olivia's spine over this time and she has been referred to a spinal specialist.

Healthwatch are speaking to Opcare and the Clinical Commissioning Group to understand why children are not routinely offered assessment and review appointments to ensure that the wheelchair they are using is meeting their needs.



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A woman with short dark hair, wearing a black and white patterned dress, is seated in a wheelchair in a kitchen. She is looking down and to the right. The background shows kitchen cabinets, a window with a green plant, and a vase of yellow flowers.

## **Modifying a wheelchair that needs replacing, in an attempt to meet changing needs**

Lucy is twenty-eight years old. She has complex health needs including progressive neuromuscular disease, lower limb deformity and curvature of the spine. As a result, she uses a wheelchair with a specialist seating system, which was provided for a five-year period under the NHS voucher scheme. Since obtaining her wheelchair, her needs have changed, rendering her chair unsuitable. Though she should be eligible for a reassessment of her needs, the local NHS commissioned service provider for wheelchairs, Opcare will not carry this out.

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Lucy moved to the Kirklees area in early 2015 with her wheelchair, which was provided by the NHS in Leeds. She contacted the local NHS commissioned service provider for wheelchairs, Opcare, for help with when she began to experience problems with her specialist seating system.

It took seven months for Lucy to obtain an initial appointment with Opcare. Although the appointment was led by two Opcare therapists, Lucy was neither physically examined nor asked about her health conditions, as had been the case in her previous wheelchair assessments.

Lucy says that Opcare therapists did not introduce themselves to her, she feels she has not been listened to and that therapists have not understood the impact of the poor seating on her life and livelihood. She also feels that the way in which she was spoken to by therapists was inappropriate and more suited to a child audience.

After asking Lucy how long she had had her current wheelchair, Opcare provided her with a cushion to address her seating problem. Lucy feels that the decision to provide a cushion as opposed to a needs reassessment was based upon financial factors as she was four years into her five-year wheelchair voucher period. The cushion did not help and over the next twelve months Lucy returned to Opcare on numerous occasions, each time to be given a different cushion. None of the cushions solved Lucy's seating problems so, becoming increasingly frustrated by the discomfort she was experiencing as well as the time it was taking to remedy the problem. Lucy she raised the issue with her physiotherapist in late August 2016. The outcome of this discussion was that Lucy suggested to Opcare that a moulded seat be considered for her. Her suggestion was declined by an Opcare therapist who, without conducting an assessment of her needs, informed her that her needs were not substantial enough to meet the criteria for moulded seating. Instead another cushion was ordered for Lucy. When it arrived, it did not fit her wheelchair so Opcare staff cut the cushion with an electric knife in an attempt to make it fit. This ruined the cushion, rendering it useless.

In January 2017, Opcare informed Lucy that it could not provide a seating solution for her as her current wheelchair will not allow for this. As her current wheelchair was paid for via an NHS voucher scheme for a five-year period and Lucy has had the wheelchair for four years, she has been informed by Opcare she will only receive a new wheelchair after five years. Lucy asked for a reassessment to which she is entitled, as her needs have changed and though Opcare gave her an appointment, no assessment of her needs was undertaken and Opcare therapists informed her that wheelchairs can only be given every five years regardless of circumstances. Two years on, Lucy has no solution to her wheelchair problems. She is very uncomfortable in her chair, which is making it very challenging for her to work. She is at risk of pressure sores and deterioration. Now angry and upset about the way she has been treated by Opcare she has made a formal complaint and feels she has no option but to fundraise to buy herself a new wheelchair privately.

Healthwatch is meeting with the Clinical Commissioning Group to understand where the problems are in the system and how things can be improved so that nobody has to experience such a distressing, lengthy process to obtain a new wheelchair. Healthwatch advised Lucy to contact Kirklees NHS Independent Health Advocacy Service for support.



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**Obtaining a new specialist wheelchair when needs have changed should not be such a lengthy process**

Katie is a young adult who needs a new wheelchair. She was supposed to receive a new wheelchair following surgery to remove a hip. One year on, she has yet to receive her new wheelchair. Her current wheelchair is uncomfortable and inadequate in terms of posture support. However, she has no option but to use it.

We use people's stories to highlight problems, and encourage the NHS to change and improve its services.  
Tell us your story today.

Katie is twenty-three years old. She has complex health needs including epilepsy, reflux and curvature of the spine.

She has had her current wheelchair for over nine years. Over a year ago she had an operation to remove a hip. This resulted in a change in her needs and it was agreed that she would receive a new wheelchair after her operation. However, over a year later, Katie has still to receive her new wheelchair.

Health professionals involved in her care have supported her need for a new wheelchair. The family does not know when a new chair will be provided in spite of their representative making numerous contacts with the Opcare.

Katie uses her wheelchair from when she gets up in the morning to when she goes to bed at night. It is neither comfortable nor provides adequate posture support for Katie and her mum is concerned that this will have a negative impact on Katie's health in the future.

Feeling that she had no other option, Katie's mum bought her a wheelchair privately. However, this has not solved Katie wheelchair problems as it has proved to be unsuitable for her needs. Katie's mum stated that "life is hard enough looking after a disabled person, without having to battle" for a wheelchair.

Healthwatch is meeting with the Clinical Commissioning Group to understand where the problems are in the system and how things can be improved so that nobody has to experience such a distressing, lengthy process to obtain a new wheelchair.



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**It has taken three years, many communications and a complaint for changing wheelchair and seating needs to be met**

Alex is a young adult with complex needs. In 2014 it became clear that his wheelchair needs had changed and so an assessment was requested on his behalf. It took three years, many communications and a complaint to the Clinical Commissioning Group before a timetable was agreed for meeting Alex's wheelchair and seating needs. Alex's needs are currently being assessed.

We use people's stories to highlight problems, and encourage the NHS to change and improve its services. Tell us your story today.

Alex is a thirty-one-year-old man with complex needs including cerebral palsy, scoliosis and epilepsy. He lives in supported accommodation and uses his wheelchair both inside and outside his home.

In 2014, it became clear that Alex's needs had changed with respect to his wheelchair and seating system. The wheelchair was no longer providing adequate posture support for Alex and this made it uncomfortable for him to sit in his wheelchair for any length of time. As a result, Alex who due to his health conditions, is unable to maintain his own posture, needed regular increased assistance from his carers to readjust him in his wheelchair so that posture support could be sustained as much as possible. He also began to display behaviour such as agitation, distress and grimacing which indicated he was in pain. Changes in his spine curvature also meant that Alex's footplate was also no longer correctly positioned. The footplates could not be adjusted and the result was that Alex's feet began dangling off the footplate. This situation was worsened due to that fact that Alex has frequent extensor seizures which cause his leg to fling outwards. This results in his foot extending against or beyond the footplate, which leads to undue force being applied to the foot in confined areas such as a lift. This is dangerous and resulted in Alex sustaining a broken foot.

Alex's mum raised her concerns to Opcare repeatedly to no avail. In August 2016, she submitted a formal complaint to the Clinical Commissioning Group (CCG). Subsequent meetings with the CCG did not result in the resolution of the problem. In February Alex's mum requested support from Healthwatch Calderdale's NHS Advocacy Service. She attended a meeting with the Clinical Commissioning Group and a Healthwatch Advocate in February 2017. Since then positive steps have been taken by Opcare to meet Alex's wheelchair needs.

Healthwatch is meeting the Clinical Commissioning Group to understand where the problems are in the system and how things can be improved so that nobody has to experience such a distressing, lengthy process to obtain equipment to meet their needs.



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