

# Azeem Ahmed





# What has been good for me

The care and support provided by all NHS staff including:-

- ❖ *hospital staff*
- ❖ *ventilation team support workers*
- ❖ *respiratory team/physiotherapists*
- ❖ *iCare*
- ❖ *Robin House and Sense*



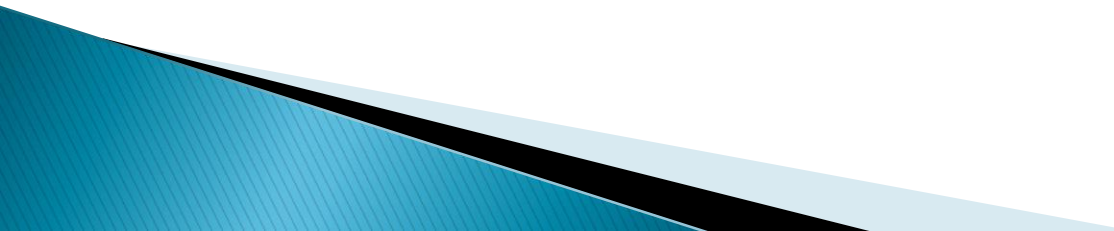
# Care and Support

Support from hospital staff and physiotherapists when I am unwell and need to be in hospital



# Care and support

Respiratory team /physiotherapists in the hospital

- ▶ They know me really well
  - ▶ They know what treatment I need to get me well
  - ▶ They treat me like an adult
  - ▶ They always listen
  - ▶ They don't mind when I phone for advice
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# Care and Support

## Ventilation Team

*Having support overnight allows my mum and dad to get a sleep at night . This makes all the difference to them and me and helps us as a family*

# School Nurse

My School nurse Pam has been very supportive of me. She has been very helpful in her role as my pathway coordinator . Pam helped and supported me when my brother Haris and my granddad passed away . She also supported and helped my family when my dad got unwell.

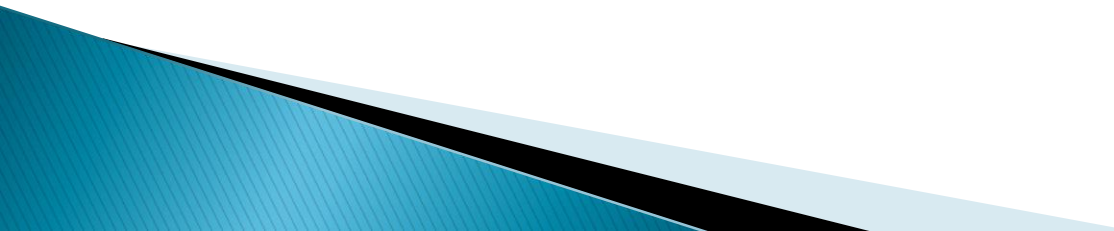
# Respite care

A blue circular logo containing the text "Robin House Childrens Hospice" in white, stacked vertically.

Robin  
House  
Childrens  
Hospice

*I have been going to Robin house for the last 14 years .Going there gives us respite as a family and we get to spend time together.*

*It's like a holiday with round the clock care.*

A decorative graphic in the bottom left corner consisting of overlapping blue and black geometric shapes.



# Respite care

Robin  
House  
Childrens  
Hospice

- ▶ They even let me do work experience with the maintenance team!



# Respite care

iCare

I Care staff look after me to give mum and dad respite this allows them to go shopping visit family and friends or just relax. They still provide respite even when I am in hospital

# Respite care

iCare

- ▶ Out and about with iCare
- ▶ Going to the cinema
- ▶ Going shopping
- ▶ Going to the park
- ▶ Doing art and craft



# Respite care



Sense

- ▶ *Sense has become a big part of my life over the last few years and I have built up really good relationships with the staff . They really help me in times of need like when my dad was in hospital*

**What is a good quality of life for me**

*Being well and staying well*

# What is a good quality of life for me

- ▶ Socialising and hanging out with friends



# What is a good quality of life for me



Looking good I like my fashion and holidays



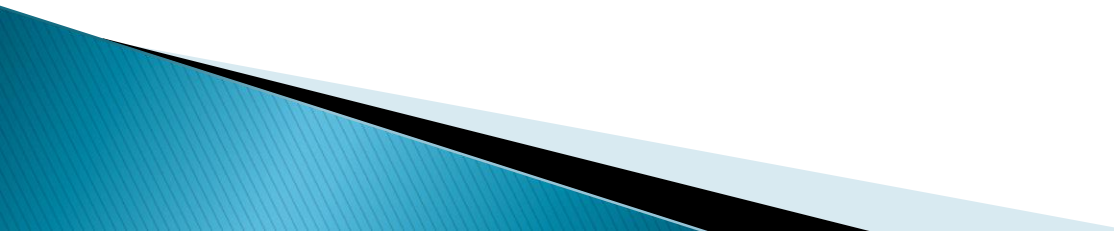
# What is a good quality of life for me



I love making lots of money



# What is a good quality of life for me

- ▶ Being in my electric chair so I can get about independently .
  - ▶ Over the years my condition has changed and Westmarc have really helped me stay as independent as possible by altering my control panel on my chair to suit my needs
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# What is a good quality of life for me

- ▶ This is really important to me as I don't like to be stuck and having to rely on someone pushing me. I like to do as many thing as possible for myself

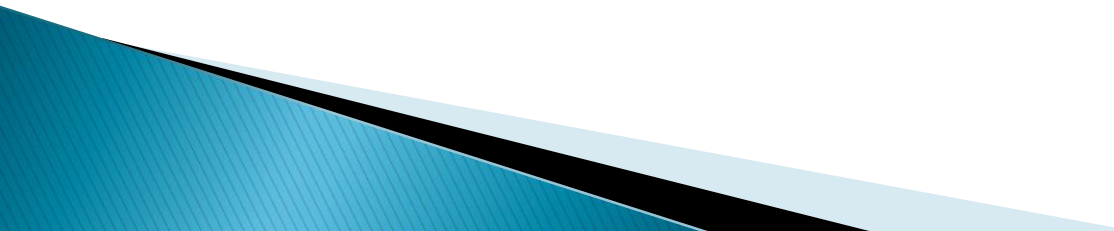


# What is a good quality of life for me

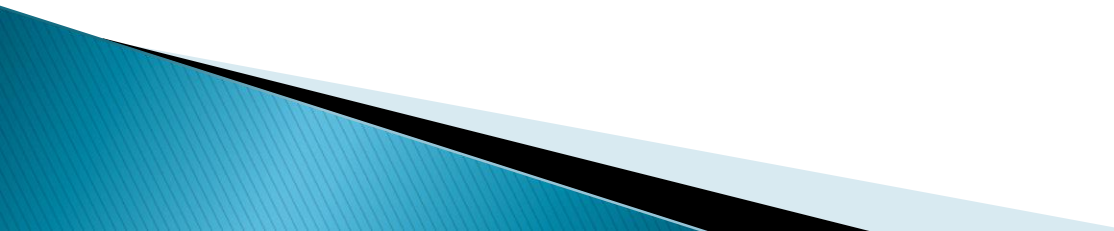


I like to buy and  
sell cars

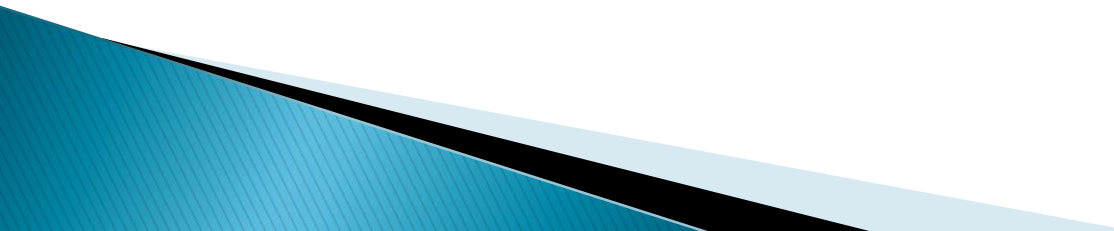
# What Matters to me

- ▶ To be listened to
  - ▶ I want to be involved in all decision regarding my ongoing care
  - ▶ I want to make choices around my care, taking into account that I am now an adult
  - ▶ I want to be as independent as much as I can
  - ▶ I want to carry on accessing all the activities that I enjoy
- 

# Challenges for me and my family

- ▶ My condition Muscular Dystrophy this challenges my mobility and restricts my movement
  - ▶ Changes in my muscles has made it harder to move my wheel chair use my phone and tablet
  - ▶ I am prone to chest infections so frequent need to be admitted to hospital for antibiotics
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# Challenges for me and my family

- ▶ Not being able to drive my own car which means I have to rely on other people to take me places
  - ▶ Unable to wash and dress and take an active part in how I want to look
  - ▶ The need for ventilation every night, how the mask feels on my face and how it can affect my skin
- 

# Challenges

A part of my Physio sessions there is my cough assist, ventilator, Nebuliser and suction which can take up a lot of time



# Challenges

*Most of my life other people have made decisions for me . I find this difficult as I have a very determined personality*

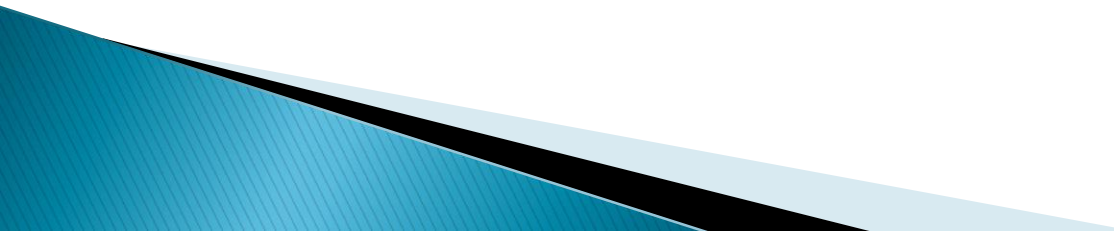


# What can CEN do to help



Help services work together. I think if all agencies worked together and shared information with each other it would make better more continuous care for everyone

# What can CEN do to help

- ▶ I am happy with the care I receive but I would like to be assisted with eating and drinking. This is very important to me.
  - ▶ I have been told I am at risk of aspirating but I feel it should be my choice to continue to eat and drink but unfortunately no one is allowed to feed me
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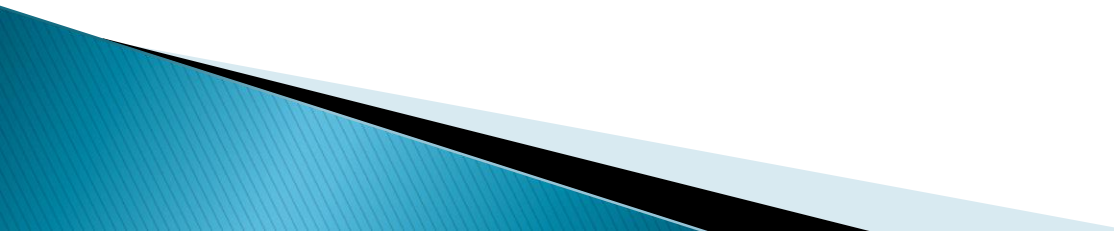
# What can CEN do to help



Advocate for key workers to coordinate my care

# Transition to Adult Services

## what is working well


- I have had a good transition so far and everyone seems to be working together with my best interests as the main goal
  - My social work team have started the process early by introducing adult services
  - I feel reassured that the level of care I have now will continue when I am fully in adults
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# Transition to Adult Services what is working well

- ▶ I was able to visit the Prince and Princess of Wales Hospice which has great facilities including art which I love .



# What will help me

- ▶ PIP, carers allowance social work funding
  - ▶ Access to a mobility scheme.
  - ▶ Additional funding from charities
  - ▶ Robin house continuing to help me access concert tickets and events .
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# What will help me achieve

*I'm very grateful for all the support I have received and the opportunities I've had meeting people and experiencing many things that many people only dream of. Social work have always taken into account the health needs of my family and provided support for us all.*

Any Questions

