


Whose life, whose choice?



This is a reflective study based on experiences over the past 5 years prescribing wheelchairs and seating for 42 young people with progressive neuromuscular disability



Treloar College is a Residential Further Education College in Hampshire for students with disabilities aged 16 to 25 years.

It welcomes students from all over Britain and from overseas and has 175 students approx 10% with progressive neuro-muscular disability.

Treloars offers a wide range of courses from A levels through vocational courses to basic skills and access courses.

Some of the A level students attend the local Further Ed College where they integrate with able bodied students.

Statement of Purpose



- Treloar College strives for excellence in Education, Therapy and care in environments which encourage disabled individuals to achieve their potential.
- We aim to provide each student with the knowledge and self confidence to take control of his/her own life.
- This means being assertive, practising independence, learning new skills, making choices, gaining qualifications and.....
- Enjoying life!

Initial details



This presentation reflects our experiences over the past 5 years looking at the wheelchair and seating provision for 42 students aged between 17 and 22 years.

- 34 Duchenne Muscular Dystrophy
- 3 Congenital Muscular Dystrophy
- 3 Spinal Muscular Atrophy
- 2 Leukodystrophy

7 female 35 male

More about the students!




- 40 use power chairs.
- 2 pushed in manual chairs with supervised power chair use.
- All hoisted for transfers.
- 5 studying A levels at Alton College
- 30 studying A levels or equivalent vocational courses.
- 7 Access or Towards Independence courses

Where are they now ?



- 7 at University / Further Ed
- 4 at home / Residential placement
- 15 still at Treloars
- 16 have died

Wheelchairs and Seating



• Chairs		• Seating	
• Private	26	• Private	25
• NHS	11	• NHS	16
• NHS awaiting funds	3	• Joint	1
• Joint funded	2		

Different wheelchair services

30

Epioc

Private



• Storm	1	19
• F55	1	4
• Spectra Plus	5	1
• Puma/Yes10	1	1
• Harrier plus	6	-
• Quantum Blast	-	1
• Apollo (Epic)	2	-
• Total	16	26

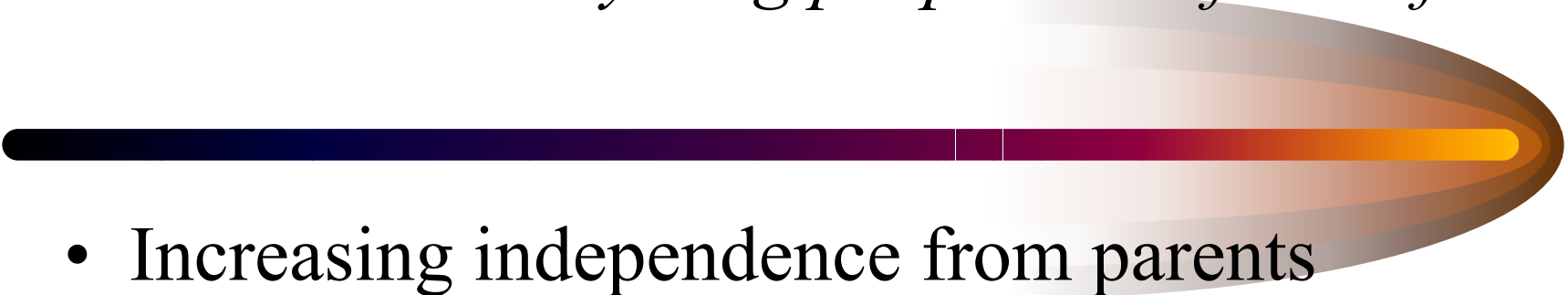
Epioc

Private



• Tilt in space	7	26
• Recline	2	25
• Lights	2	26
• Riser	—	2

What do these young people want from life?


- 
- Increasing independence from parents
 - To explore the wider world
 - To look and feel good
 - To stay up/go out late
 - Girlfriends/boyfriends
 - **To be comfortable**

Interests

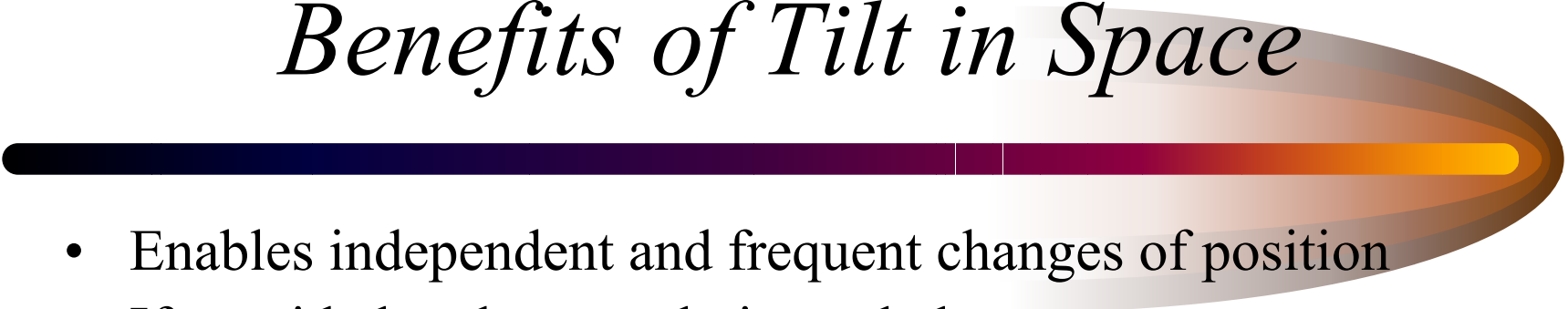


- Sport
- Music
- Shopping
- Pubs and night clubs
- Computers and play stations
- Films

How can the right wheelchair and seating help?

- 
- Functions, (Tilt in space, recline, lights)
 - Speed
 - Range
 - Street cred / colour choice
 - Comfort and pressure relief
 - Optimising function

Benefits of Tilt in Space



- Enables independent and frequent changes of position
- If provided early enough, it can help to prevent development of forward lean sitting position.
- Reduces development of neck contractures and chin poking.
- Reduces the need for intrusive and uncomfortable trunk support and harnesses
- Maximum pressure distribution
- Assists toileting and placement of slings
- Reduces fatigue and provides relaxing/ resting position
- Safer travelling position

Common Posture

- Forward lean sitting or side lean sitting
- Often use anterior tilt of pelvis
- They lean on trays or arm rests.





Pressure relief



- They have full sensation
- Use chairs routinely up to 16 hours a day
- Cannot move themselves
- Many are very thin
- Lean onto trays or armrests

Funding



- NHS provision very variable in different areas.
- Several students report negative contact
- Some services refuse to fund tilt in space chairs or seating for private chairs, others will !
- Long waiting lists for assessment and provision

- Charities that we have used include Joseph Patrick Memorial Trust, Action for Kids, Whizz Kids, Variety Club, and our own charity, IMPact
- Maintenance and repairs are usually funded by student and parents.

Conclusions



- The right equipment enables them to live an active teenage lifestyle and be significantly more comfortable and independent of carers.
- This can make a major difference to their self esteem and quality of life
- Joint funding by wheelchair services and charities might enable better equipment to be provided more quickly but ownership, insurance and responsibility issues make this complicated.

These young adults want



- To be comfortable
 - To have some independence
 - To make the most of their short lives
-
- Is this too much to ask ?

How can we help?



- It isn't easy
- Equipment is expensive
- There are other problems and difficulties

Can we work together to improve the quality of their lives?

I feel I am not here!

I feel I am not here,

My wheelchair is here but I am not

People see the chair before they see me

I am living the life of my chair

The life of my disability

It is like “I” don’t exist.