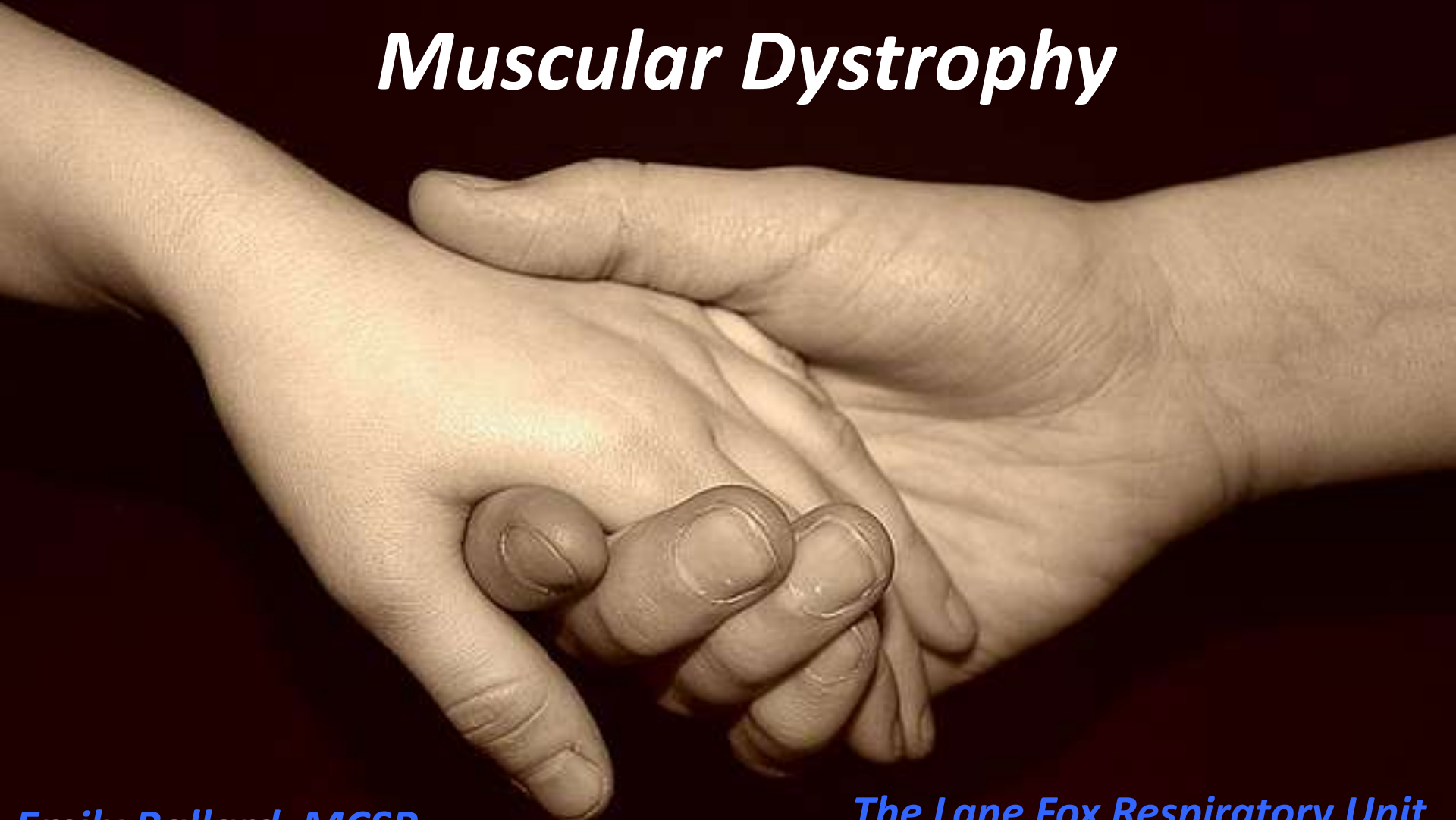


# *Transitional Care in Duchenne Muscular Dystrophy*



*Emily Ballard MCSP*

*Specialist Transitional Care Coordinator  
Progressive Neuromuscular Disease*

*The Lane Fox Respiratory Unit*

Guy's and St Thomas'



NHS Foundation Trust

***Duchenne Muscular Dystrophy is no longer  
just a childhood disease***

***Teenagers often see their healthcare  
as a low priority***

***The teenage years are high risk for respiratory deterioration and early respiratory screening is essential***

***Respiratory specialist involvement  
and care coordination reduces  
unplanned admissions***

# Since January 2009:

- No unplanned first crisis admissions
- No admissions requiring tracheostomy or ITU in our own patient cohort

We continue to see unplanned crisis admissions requiring ITU and tracheostomy as referrals from outside our cohort

***Respiratory Care Lecture***  
***Dr Nicholas Hart 2.30pm***

***What else happens in the teenage years?***

***How do our patients feel about transition?***



***Growing up and transition***

- In 2008 We hypothesised that the transitional care needs were not currently being addressed
- We designed a questionnaire as a qualitative assessment of our current neuromuscular service
- The questionnaire was issued to 39 DMD patients
- Age between 14 and 36 years (pre and post transition)
- 24 questionnaires were returned and analysed

- We hypothesised that the transitional care needs were not currently being addressed
- **We designed a questionnaire as a qualitative assessment of our current neuromuscular service**
- The questionnaire was issued to 39 DMD patients
- Age between 14 and 36 years (pre and post transition)
- 24 questionnaires were returned and analysed

- We hypothesised that the transitional care needs were not currently being addressed
- We designed a questionnaire as a qualitative assessment of our current neuromuscular service
- **The questionnaire was issued to 39 DMD patients**
- Age between 14 and 36 years (pre and post transition)
- 24 questionnaires were returned and analysed

- We hypothesised that the transitional care needs were not currently being addressed
- We designed a questionnaire as a qualitative assessment of our current neuromuscular service
- The questionnaire was issued to 39 DMD patients
- **Age between 14 and 36 years (pre and post transition)**
- 24 questionnaires were returned and analysed

- We hypothesised that the transitional care needs were not currently being addressed
- We designed a questionnaire as a qualitative assessment of our current neuromuscular service
- The questionnaire was issued to 39 DMD patients
- Age between 14 and 36 years (pre and post transition)
- **24 questionnaires were returned and analysed**

- **42% were extremely or moderately worried about transition**
- 63% were told little or nothing by the paediatric team and 58% were told little or nothing by the adult team of what to expect on transferring to adult service
- 79% had not met the adult team prior to transferring into adult services
- 38% had poor or very poor continuation of care and overlap of services between adult and paediatrics
- 79% were given little or no preparation for transfer from paediatric to adult services and 42% had no prior knowledge of the specialist respiratory unit
- 100% reported it would be helpful to have an identified person to link the services and 96% reported it would be helpful to have a specific person to provide advice for management of medical crises

- 42% were extremely or moderately worried about transition
- 63% were told little or nothing by the paediatric team and 58% were told little or nothing by the adult team of what to expect on transferring to adult service
- 79% had not met the adult team prior to transferring into adult services
- 38% had poor or very poor continuation of care and overlap of services between adult and paediatrics
- 79% were given little or no preparation for transfer from paediatric to adult services and 42% had no prior knowledge of the specialist respiratory unit
- 100% reported it would be helpful to have an identified person to link the services and 96% reported it would be helpful to have a specific person to provide advice for management of medical crises

- 42% were extremely or moderately worried about transition
- 63% were told little or nothing by the paediatric team and 58% were told little or nothing by the adult team of what to expect on transferring to adult service
- **79% had not met the adult team prior to transferring into adult services**
- 38% had poor or very poor continuation of care and overlap of services between adult and paediatrics
- 79% were given little or no preparation for transfer from paediatric to adult services and 42% had no prior knowledge of the specialist respiratory unit
- 100% reported it would be helpful to have an identified person to link the services and 96% reported it would be helpful to have a specific person to provide advice for management of medical crises

- 42% were extremely or moderately worried about transition
- 63% were told little or nothing by the paediatric team and 58% were told little or nothing by the adult team of what to expect on transferring to adult service
- 79% had not met the adult team prior to transferring into adult services
- **38% had poor or very poor continuation of care and overlap of services between adult and paediatrics**
- 79% were given little or no preparation for transfer from paediatric to adult services and 42% had no prior knowledge of the specialist respiratory unit
- 100% reported it would be helpful to have an identified person to link the services and 96% reported it would be helpful to have a specific person to provide advice for management of medical crises

- 42% were extremely or moderately worried about transition
- 63% were told little or nothing by the paediatric team and 58% were told little or nothing by the adult team of what to expect on transferring to adult service
- 79% had not met the adult team prior to transferring into adult services
- 38% had poor or very poor continuation of care and overlap of services between adult and paediatrics
- **79% were given little or no preparation for transfer from paediatric to adult services and 42% had no prior knowledge of the specialist respiratory unit**
- 100% reported it would be helpful to have an identified person to link the services and 96% reported it would be helpful to have a specific person to provide advice for management of medical crises

- 42% were extremely or moderately worried about transition
- 63% were told little or nothing by the paediatric team and 58% were told little or nothing by the adult team of what to expect on transferring to adult service
- 79% had not met the adult team prior to transferring into adult services
- 38% had poor or very poor continuation of care and overlap of services between adult and paediatrics
- 79% were given little or no preparation for transfer from paediatric to adult services and 42% had no prior knowledge of the specialist respiratory unit
- **100% reported it would be helpful to have an identified person to link the services and 96% reported it would be helpful to have a specific person to provide advice for management of medical crises**

- The data showed that DMD patients were concerned about the period of transition into adult services and did not receive adequate information about the process or the teams involved
- All the patients surveyed expressed a specialist link between services would be useful
- This is in line with the DOH's guidance on transition of care for chronic disease

- These data show that DMD patients are concerned about the period of transition into adult services and do not receive adequate information about the process or the teams involved
- **All the patients surveyed expressed a specialist link between services would be useful**
- This is in line with the DOH's guidance on transition of care for chronic disease

- These data show that DMD patients are concerned about the period of transition into adult services and do not receive adequate information about the process or the teams involved
- All the patients surveyed expressed a specialist link between services would be useful
- **This is in line with the DOH's guidance on transition of care for chronic disease**

***We need to repeat this questionnaire***

# ***The GSST Model of Transition***



**P** Parking on Lower Ground level

**P** Parking on Lower Ground level

**P** Parking on Lower Ground level

Main Entrance

Vehicle Entrance

North Wing  
A

F Outpatients  
Pharmacy

Governors' Hall Suite  
Central Hall  
South Wing  
Shepherd Hall  
The Lane Fox Respiratory Unit

East Wing  
E

Accident & Emergency

Evelina Children's Hospital

St Thomas' House

Staff Gym

Medicinema  
Prideaux Building

Lambeth Palace Road  
C10  
77  
507

Posterior Crossings

C11  
77.5

Archbishop's Park

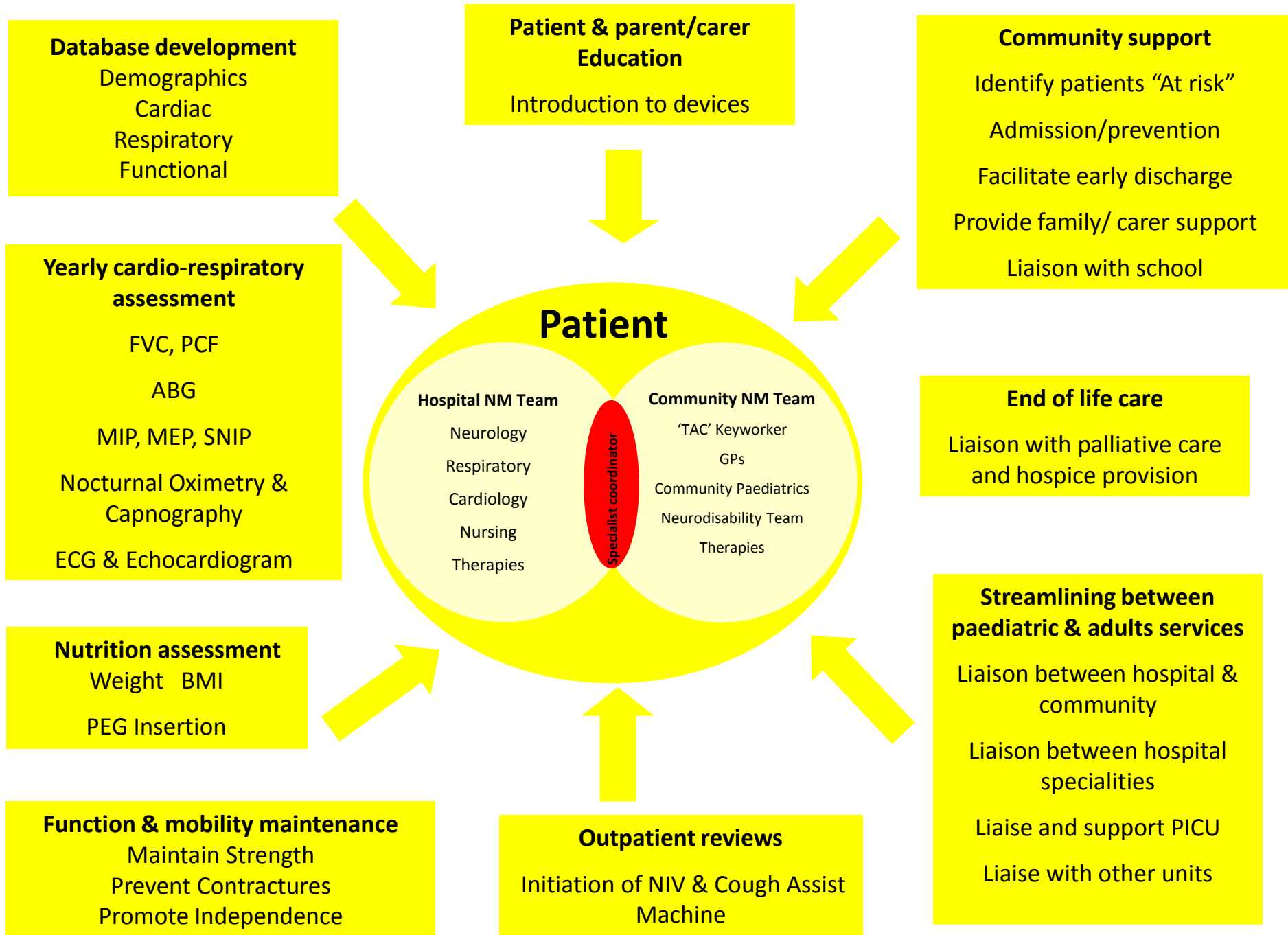
drop off only



***All patient care is managed  
by one trust on one site***



**2 minutes walk**



***How do we plan for Transition?***

- Early planning
- Team approach/ Joint clinics
- Care plans
- Flexible according to individual needs
- Involving community teams is vital
- Review care package (continuing healthcare assessment?)
- Consider: Independent living/ further education/ access to work/ holidays
- Equipment provision- Contracts?



# ***Effective communication***



Community  
Therapists

School,  
College,  
University  
or Work

Hospice  
and Respite  
Nursing

**SPECIALIST CENTRE**

District

Care Team

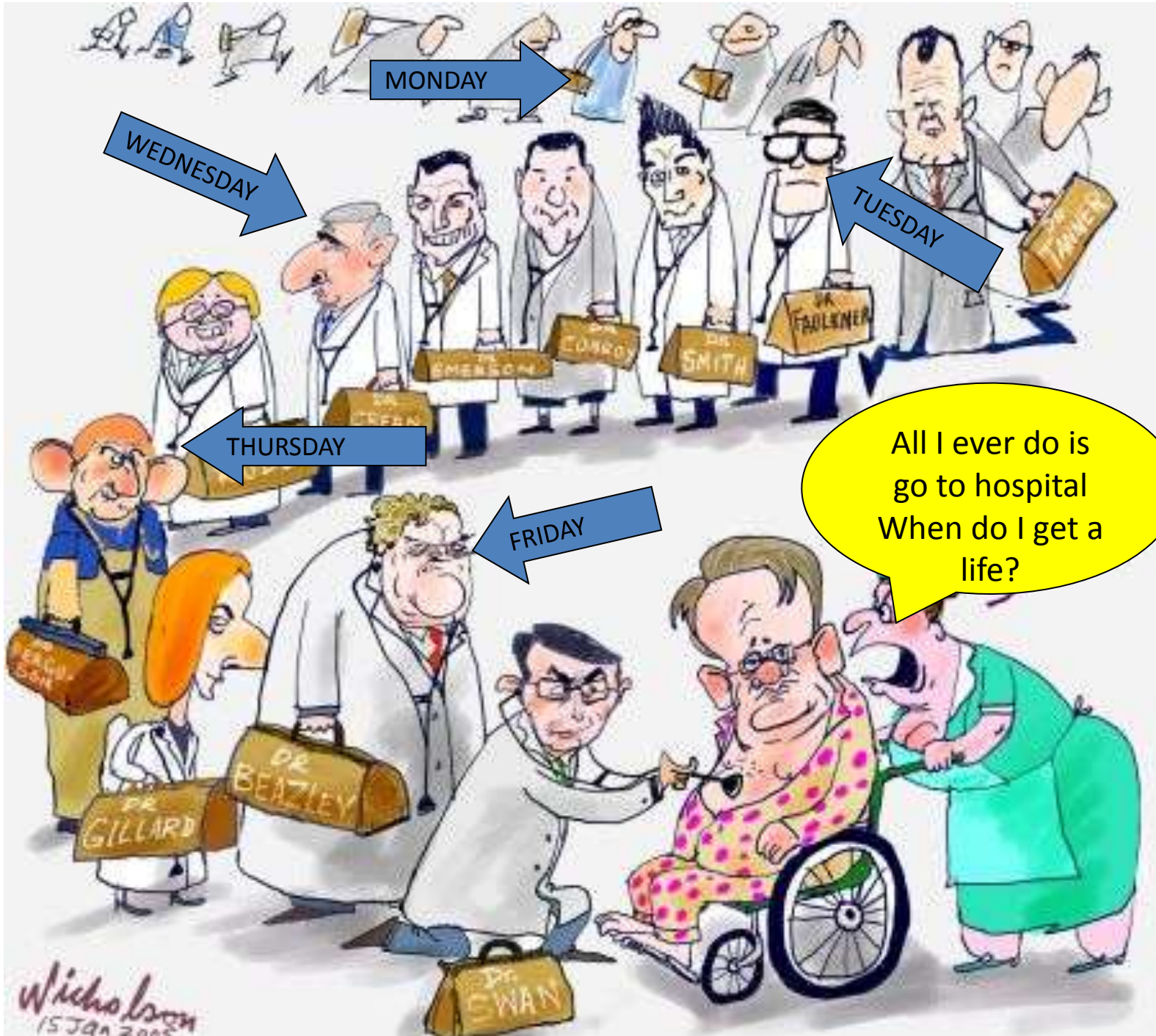
Care Teams

Wheelchair  
Services

GP and  
Local  
Hospitals

***The older they get the bigger the care team***

5  
8



MONDAY

WEDNESDAY

TUESDAY

THURSDAY

FRIDAY

All I ever do is go to hospital When do I get a life?

Nicholson  
15 Jan 2005

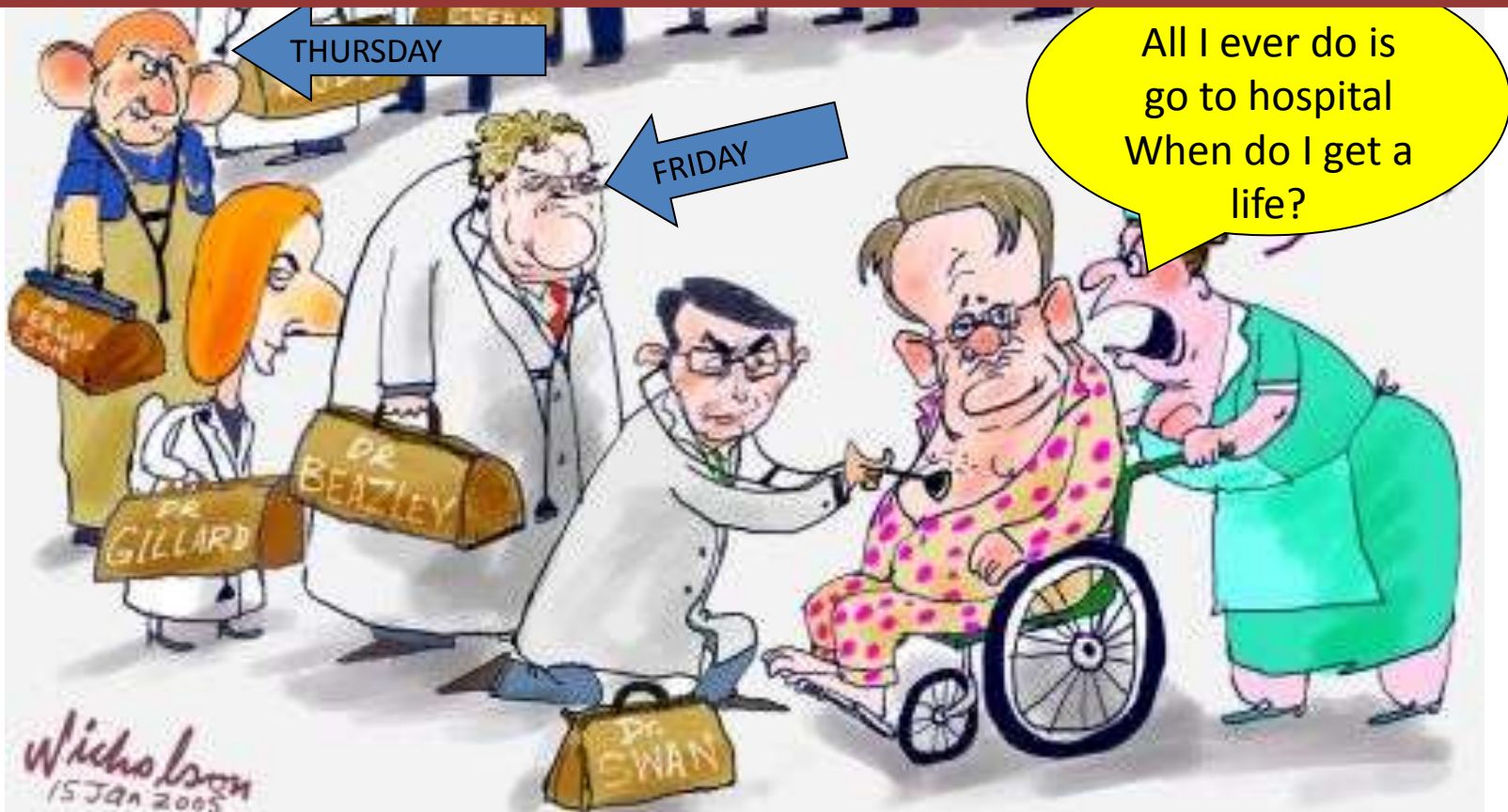


MONDAY

WEDNESDAY

TUESDAY

# ***Coordinated care and streamlined clinics***



THURSDAY

FRIDAY

All I ever do is go to hospital  
When do I get a life?

Nicholson  
15 JAN 2005

***Our aim is to maximise quality of life***



- We have cut the number of appointments reducing unnecessary travel
- We combine appointments whenever possible
- We now provide adult MDT clinics with ECHO and ECG on the same day

- We have cut the number of appointments reducing unnecessary travel
- **We combine appointments whenever possible**
- We now provide adult MDT clinics with ECHO and ECG on the same day

- We have cut the number of appointments reducing unnecessary travel
- We combine appointments whenever possible
- We now provide adult MDT clinics with Cardiology (ECHO and ECG) on the same day

***Adolescent environment?***

- Higher staff to patient ratio than adult wards
- Social stimulus
- Entertainment equipment
- Promotion of independence
- Appropriate communication facilities
- Access to carer/ family accommodation

- Higher staff to patient ratio than adult wards
- **Social stimulus**
- Entertainment equipment
- Promotion of independence
- Appropriate communication facilities
- Access to carer/ family accommodation

- Higher staff to patient ratio than adult wards
- Social stimulus
- **Entertainment equipment**
- Promotion of independence
- Appropriate communication facilities
- Access to carer/ family accommodation

- Higher staff to patient ratio than adult wards
- Social stimulus
- Entertainment equipment
- **Promotion of independence**
- Appropriate communication facilities
- Access to carer/ family accommodation

- Higher staff to patient ratio than adult wards
- Social stimulus
- Entertainment equipment
- Promotion of independence
- **Appropriate communication facilities**
- Access to carer/ family accommodation

- Higher staff to patient ratio than adult wards
- Social stimulus
- Entertainment equipment
- Promotion of independence
- Appropriate communication facilities
- **Access to carer/ family accommodation**

# Living with long term NIV



***How can we keep young people  
out of hospital?***



***Provide portable equipment***



***Provide 24  
hour technical  
support***

***Provide management plans***

# ***Chest Crisis***

# Home Care Plan for Chest Crisis Management

## Symptoms to watch out for

- Chesty cough
- Fever
- Sleep disturbance night or sleepy in day
- Lack of appetite
- Feeling 'under the weather'

## What to do straightaway

- Check temperature
- If > 37.5 treat with paracetamol and contact GP to start antibiotic treatment
- Use cough assist +/- chest physiotherapy
- Use mask ventilator as well if breathless
- Telephone Lane Fox Respiratory Unit

## Move to second line management if any of the symptoms listed below:

- Increasing use of mask ventilator
- Unable to breathe properly when off it
- Fast, shallow or deep gasping breathing
- Poor fluid intake
- Increased secretions or inability to clear these with cough assist +/- chest physiotherapy
- Yellow/green sputum
- Blue hands or lips
- Rapid decline in breathing
- Difficulty talking in full sentences
- More sleepy than normal

## 2<sup>nd</sup> line management

- Contact Lane Fox Respiratory Unit on 020 7188 3435 or 020 7188 3434 OR
- Contact Emily Ballard, Transitional Care Coordinator on 0207 188 8069 or bleep 2433

**If urgent call the switchboard on 0207 188 7188 and ask for the 'Nurse Advisor Lane Fox Unit' on bleep 1572 who is available 24 hours a day**

## 3<sup>rd</sup> line emergency management (unconscious or severe distress)

- Call 999 for admission to local hospital
- Use mask ventilator in ambulance
- Ask A&E staff to call LFU on arrival

# *Impaired Cough*

*The inability to cough out airway secretions is the main cause of respiratory failure and death in patients with neuromuscular diseases*



***Home management***

***Teach Manual Physiotherapy  
Techniques***

# ***Lung Volume Recruitment***



Air stacking can be done using

- An LVR bag
- Glossopharyngeal breathing
- Volume ventilator

***Provision of home cough assist?***



***Practical respiratory workshop  
at 3-3.30pm***

# ***Bowel Management Plan***

<b>What If.....</b>	<b>What to Take...</b>
<b>Not had bowels opened for 1-2 days.</b>	<b>Movicol x 1 sachet twice a day. Continue with Senna. Increase Fluid intake</b>
<b>Going regularly</b>	<b>Continue with Senna.</b>
<b>Not had bowels opened for over 3 days</b>	<b>Continue with Senna. Movicol x 1 sachet 3-4 x per day. Increase fluid intake.</b>
<b>Bowels opened too much!!</b>	<b>Stop everything for 24 hrs then re-start senna.</b>
<b>Diarrhoea</b>	<b>Stop everything. Consider specimen to GP.</b>

# End of life scenarios

<u>Problem</u>	<u>What to do</u>	<u>Contact Day/Night</u>	<u>Contact if worsening/ Not Resolving</u>
<b>NG Blocks</b>	Try flushing with 10-20mls of fizzy cola or grapefruit juice. If not working try luke warm water. Try Clog -Zapper. Leave insitu for 5-10 mins then try flushing again.	Community Dietician Tel: District Nurses: Tel:	Lane Fox unit : 0207 188 3434
<b>Vomiting/ feeling nauseous</b>	Stop Feed. Flush with 10 mls water only. Consider anti -sickness medicine. Ensure NGT still in same place		GP Dr Tel:
<b>Increased sputum production</b>	Use Cough assist machine. Saline Nebulisers as required. – Helps loosen secretions Consider Antibiotics	GP Dr Tel:	Lane Fox unit : 0207 1883434
<b>More breathless and on NIV</b>	Give 5 mls Oromorph via NGT - after 10 mins if not resolving give another 5 mls Oromorph Add oxygen 2L/min	Call GP Dr Tel: Call Palliative care team Tel :	Lane Fox unit : 0207 188 3434
<b>Agitated Or Distressed</b>	Give 5 mls Oromorph liquid via NGT Repeat if not resolved after 5-10 mins Consider 1x Diazepam suppositories if possible to administer.	Call GP: Call Lane-Fox unit Tel: 02071883434	Call Palliative care team Tel :
<b>Pain or discomfort</b>	Paracetamol 1gram via NGT. Ibuprofen 400mg via NGT If not resolving give 5 mls Oromorph	Call GP Dr Tel or Lane-Fox Unit	Call Lane-Fox Unit Tel: 0207 188 3434
<b>Drowsy or Unresponsive</b>	Call GP and Lane-Fox.	Call GP Tel: Or District Nurses Tel:	Lane-Fox Unit 0207 188 3434



# ***Provision of Community Outreach***

# ***Link with Community Services***

- Health
  - Nursing/AHP-training and support
  - Consider Dentistry/ Opticians at home
  - Palliative care
- Social
  - Care Packages
  - Respite and short breaks
  - Holidays
  - Education/ Work

- **Joint working**
- Building relationships
- Sharing skills and information
- Supportive education and open communication channel
- Joint team planning for patients
- Improved use of services
- Improved quality of care and patient experience

- Joint working
- **Building relationships**
- Sharing skills and information
- Supportive education and open communication channel
- Joint team planning for patients
- Improved use of services
- Improved quality of care and patient experience

- Joint working
- Building relationships
- **Sharing skills and information**
- Supportive education and open communication channel
- Joint team planning for patients
- Improved use of services
- Improved quality of care and patient experience

- Joint working
- Building relationships
- Sharing skills and information
- **Supportive education and open communication channel**
- Joint team planning for patients
- Improved use of services
- Improved quality of care and patient experience

- Joint working
- Building relationships
- Sharing skills and information
- Supportive education and open communication channel
- **Joint team planning for patients**
- Improved use of services
- Improved quality of care and patient experience

- Joint working
- Building relationships
- Sharing skills and information
- Supportive education and open communication channel
- Joint team planning for patients
- **Improved use of services**
- Improved quality of care and patient experience

- Joint working
- Building relationships
- Sharing skills and information
- Supportive education and open communication channel
- Joint team planning for patients
- Improved use of services
- **Improved quality of care and patient experience**

# ***Promotion of independent living***



***Maximise social opportunities***



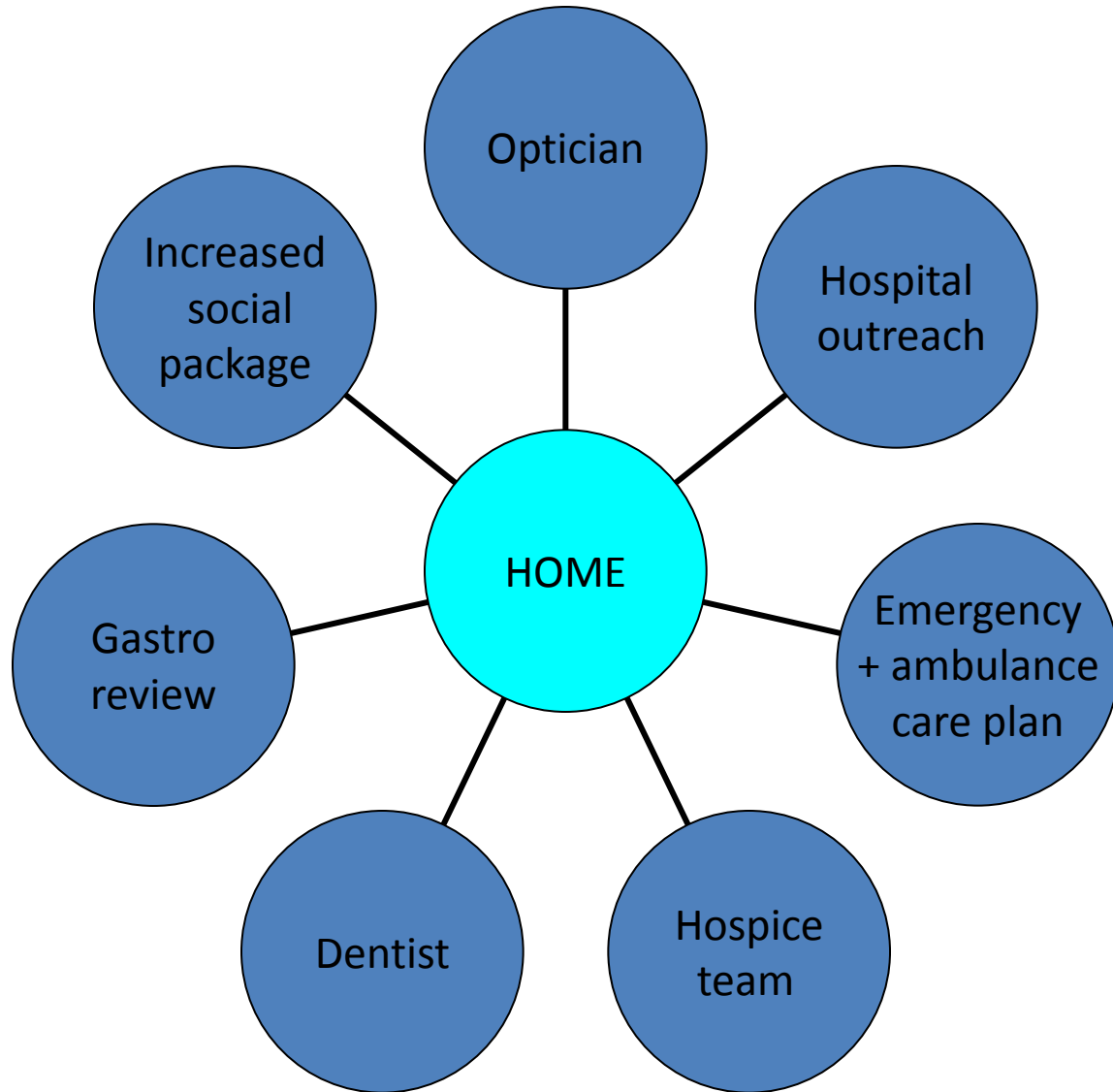


## Air travel – a guide for Lane Fox Unit patients

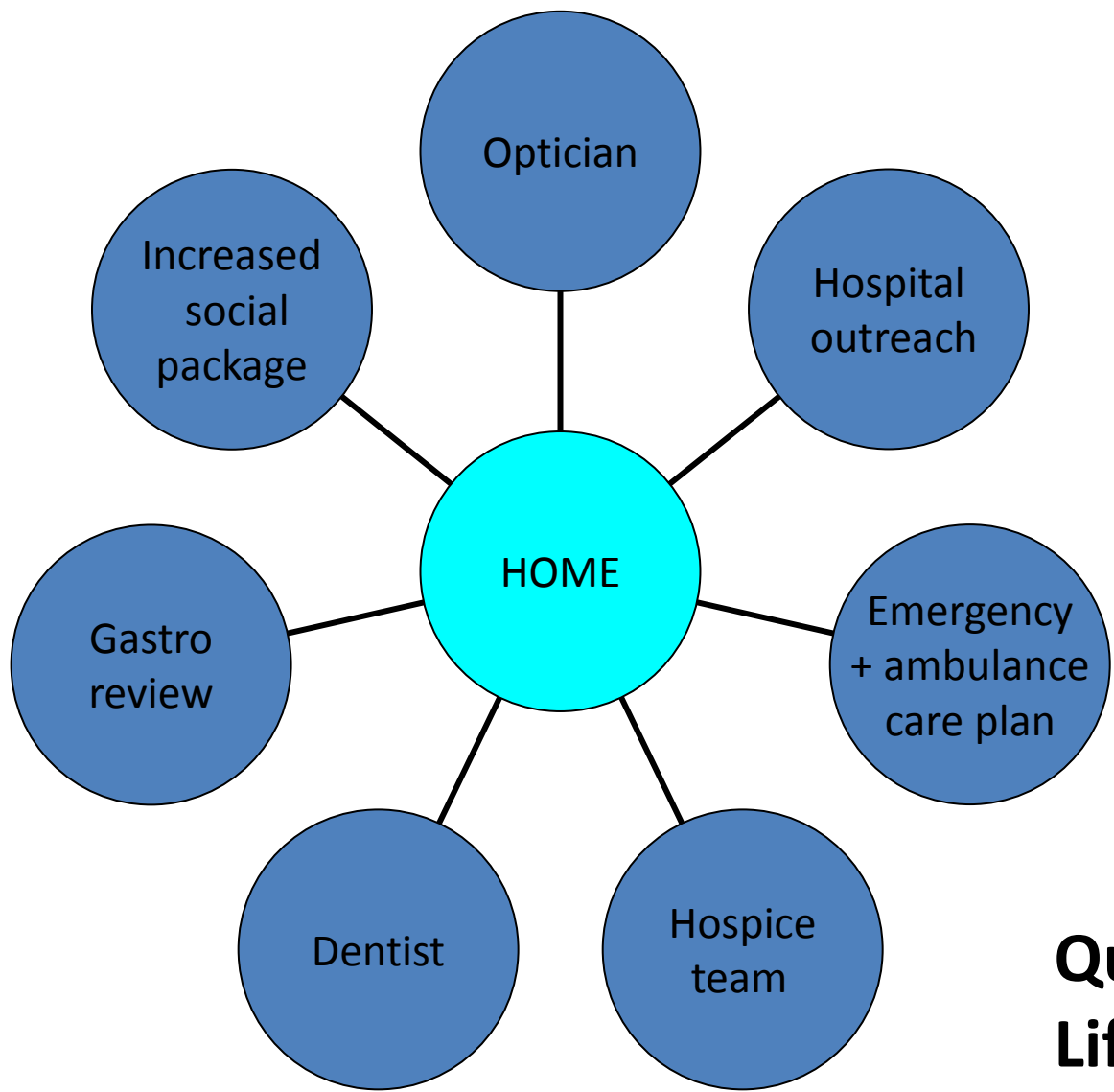
- Medical review prior to travel
- Comprehensive Medical summary
- Emergency Contacts
- Back up ventilator and disposables
- Oxygen if required
- Appropriate insurance
- Inform airline
- Complete MEDIF/ INCAD forms
- Antibiotics

# ***Meeting complex care: Case Study 1***

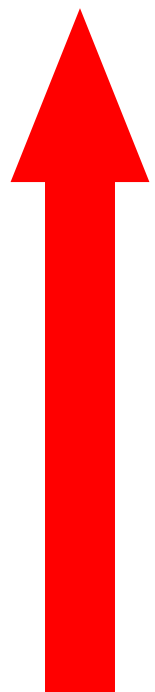
- 22 yr old with DMD
  - 24 hour non invasive ventilation
  - Frequent admissions to hospital
  - Extensive investigations (Gastrointestinal)
  - Increasing difficulties with travel
  - No emergency support plan
  - Poor social access
  - Declining mood



**Hospital admissions**



**Quality of Life**

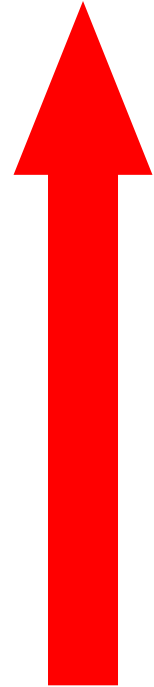
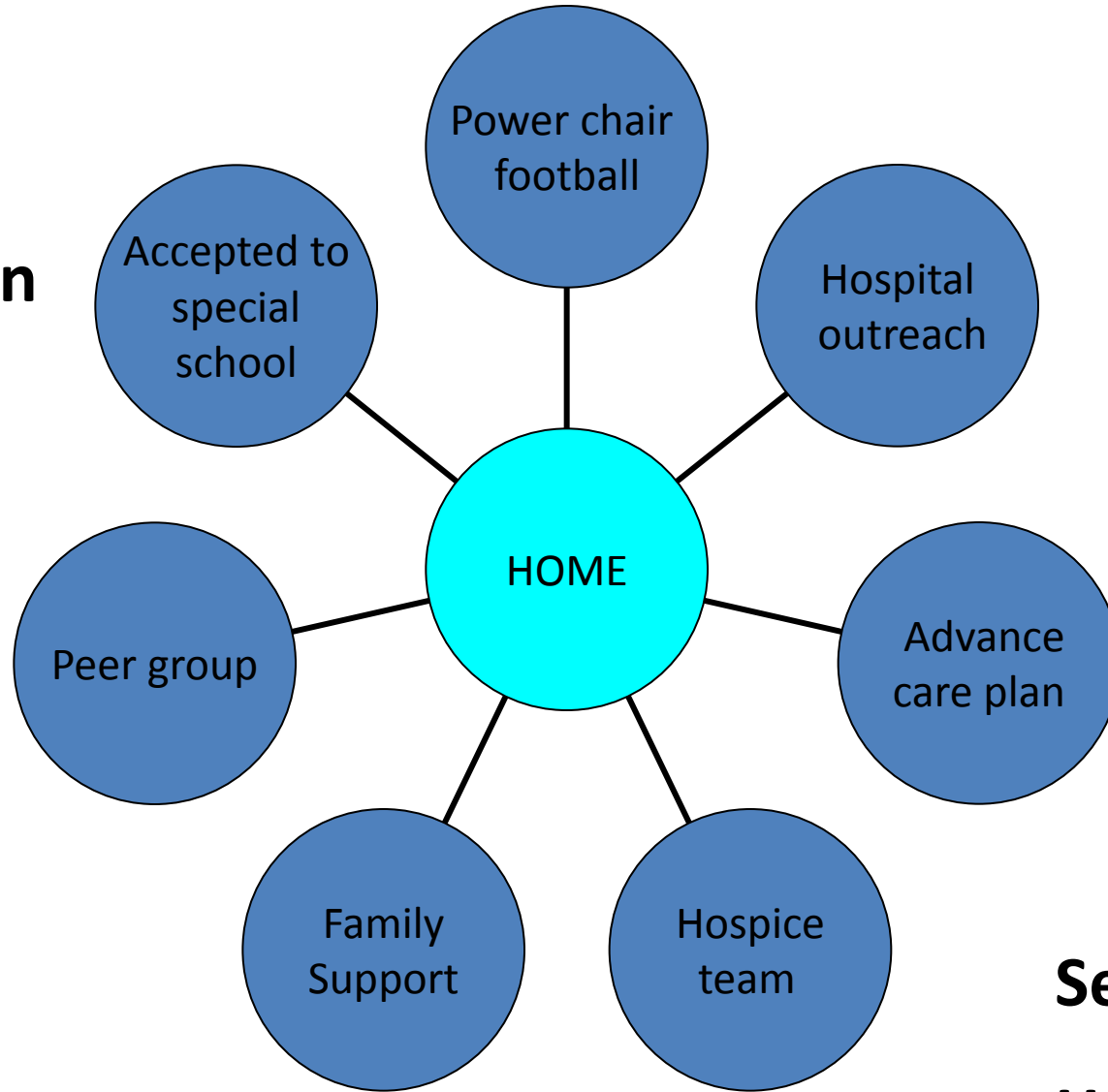
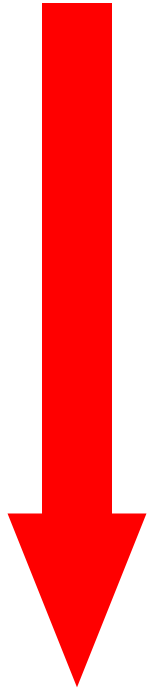


# ***Meeting complex care: Case Study 2***

- 17 year old DMD
  - Recent decline now :24 hour non invasive ventilation dependence
  - Exclusion from school (unable to meet needs)
  - No emergency support plan
  - Poor social access and no peer group
  - Declining mood



**Social  
Isolation**



**Self Worth  
Happiness**

***Our service is unique***





---

**Access to Specialist  
Neuromuscular Care:  
The Walton Report**

---

All Party Parliamentary Group  
for Muscular Dystrophy

---

---

## Section 4

### Evidence Summary

#### Transition into adulthood

Oral evidence was provided by:

*David Abbott – Senior Research Fellow at the Norah Fry Research Centre, University of Bristol*

*Emily Ballard – Specialist Transitional Care Therapist at the Lane Fox Unit, Guy's and St Thomas' NHS Foundation Trust, London*

*Dr Nicholas Hart – Clinical Research Consultant and Honorary Senior Lecturer in Respiratory and Critical Care Medicine at the Lane Fox Unit, Guy's and St Thomas' NHS Foundation Trust, London*

*Stuart Reid – Solihull, living with Duchenne muscular dystrophy*

48. We were extremely alarmed to hear about the severe lack of essential long-term assistance in transition planning. David Abbott, who has been conducting research looking in detail at transition into adulthood for young men with Duchenne muscular dystrophy, reported to us:

It seemed shocking that 20 years on from [national policies setting out] basic duty and frameworks around transition that should kick in at around 14, more than half of families couldn't recall any structured transition planning, looking back or currently.

49. We heard first-hand evidence that adult services lack the organised structure that exists in paediatric services. Stuart Reid explained his perspective on the service that he has personally experienced and the problems at transition to adult services:

Paediatric services are more structured and people seem to know what they're doing more. I had a particularly good social worker when I was younger.

Further, a recurrent problem about which we heard from several expert witnesses relates to the paucity and weakness of adult neuromuscular services in many parts of the country. Even where there are reasonable or good paediatric services in place, the provision of adult services is generally much weaker and this is unacceptable. Where good multi-disciplinary services are well co-ordinated, they involve specialities such as genetics, a muscle pathology service, cardiology, respiratory and cardiac support and specialist physiotherapy. The successful development and management of specialist care leads to a growing population of adults who in earlier times would not have survived, and these people have a right to continuing, high quality support to ensure they enjoy the best possible quality of life, as in some other European countries. We call on health service commissioners, local authorities and the local government associations to ensure they develop effective plans to guarantee they meet the comprehensive health and social care needs of this growing number of adults. *(Recommendation 11)*

## Section 4

### Evidence Summary

#### Transition into adulthood

Oral evidence was provided by:

*David Abbott – Senior Research Fellow at the Norah Fry Research Centre, University of Bristol*

*Emily Ballard – Specialist Transitional Care Therapist at the Lane Fox Unit, Guy's and St Thomas' NHS Foundation Trust, London*

*Dr Nicholas Hart – Clinical Research Consultant and Honorary Senior Lecturer in Respiratory and Critical Care Medicine at the Lane Fox Unit, Guy's and St Thomas' NHS Foundation Trust, London*

*Stuart Reid – Solihull, living with Duchenne muscular dystrophy*

48. We were extremely alarmed to hear about the severe lack of essential long-term assistance in transition planning. David Abbott, who has been conducting research looking in detail at transition into adulthood for young men with Duchenne muscular dystrophy, reported to us:

It seemed shocking that 20 years on from [national policies setting out] basic duty and frameworks around transition that should kick in at around 14, more than half of families couldn't recall any structured transition planning, looking back or currently.

49. We heard first-hand evidence that adult services lack the organised structure that exists in paediatric services. Stuart Reid explained his perspective on the service that he has personally experienced and the problems at transition to adult services:

Paediatric services are more structured and people seem to know what they're doing. In the adult services, it's much more ad hoc and people seem to be

Further, a recurrent problem about which we heard from several expert witnesses relates to the paucity and weakness of adult neuromuscular services in many parts of the country. Even where there are reasonable or good paediatric services in place, the provision of adult services is generally much weaker and this is unacceptable. Where good multi-disciplinary services are well co-ordinated, they involve specialities such as genetics, a muscle pathology service, cardiology, respiratory and cardiac support and specialist physiotherapy. The successful development and management of specialist care leads to a growing population of adults who in earlier times would not have survived, and these people have a right to continuing, high quality support to ensure they enjoy the best possible quality of life, as in some other European countries. We call on health service commissioners, local authorities and the local government associations to ensure they develop effective plans to guarantee they meet the comprehensive health and social care needs of this growing number of adults. *(Recommendation 11)*

50. We received very helpful evidence regarding an explanation of transition services in the context of specialist health care. Dr Nicholas Hart gave us an insight into the overlap of different services within specialist multi-disciplinary care:

Transition is difficult to pinpoint as a clinician in terms of start and end – 14, 18? There is only one transition service – in neurology. In respiratory, I only come in from about the age of 12. A cardiologist may be seen but the cardiac complications are later on. People are slotting in. We are in a co-ordinating role and pull in the specialist services as needed. We are allowed to have this set-up because we have the support.

51. We gathered further evidence of the long distances that patients travel to access specialised neuromuscular services at specialist centres. Dr Nicholas Hart gave an overview of how far people come to the Lane Fox Unit:

We have referrals from Birmingham and Southampton. Although the service stretches down to the south coast, we take patients from many different parts of the country, partly driven by patient choice through GP referral.

52. We had clear evidence that young people are frequently frustrated by over-reliance on family support and care. Stuart Reid told us how he is often forced to rely on his parents for his care:

I need to get extra funding from the local health authorities. Mum or Dad sometimes has to care for me during the night once or twice a week. I don't want to have to rely on them. I want them to be able to get on with their lives. My care assistant was meant to come with me. Dad had to cancel business meetings to come with me today to help me.

53. After hearing about the specialist multi-disciplinary team that is in place at the Lane Fox Unit, this further highlights that young people greatly benefit when all aspects of specialist care and support are put in place. Good practice must be shared and replicated across the country.

**We call on the Government and commissioners to take urgent action to make sure that a named transition co-ordinator is in place for each young person with a neuromuscular condition who is moving from paediatric to adult services. We heard evidence that transition services to provide support to young people when they move from paediatric to adult services are very weak in many parts of the country. (Recommendation 10)**

54. We recognise the need for good links to be established and maintained between a specialist centre and the community, as exemplified by Emily Ballard during her evidence submission:

I have been doing a lot of education with community teams and sharing my skills so that hospice staff, community nurses and community physios

feel confident with the new equipment for these patients and they understand the disease needs.

A community nurse with adults who has not dealt with the disease and doesn't know what to do – if we can support and educate them then they will be able to deal with them in the future rather than saying that the patient should just go to the specialist service and do everything there. There is a huge role for joint work with the community teams and that has been really successful so far.

55. The joint working described here should be developed and implemented across the country. Patients prefer to access integrated services as close to their home as possible – provided they are comprehensive and good quality. This clearly results in financial savings compared with referrals to attend specialist centres some distance away.

50. We received very helpful evidence regarding an explanation of transition services in the context of specialist health care. Dr Nicholas Hart gave us an insight into the overlap of different services within specialist multi-disciplinary care:

Transition is difficult to pinpoint as a clinician in terms of start and end – 14, 18? There is only one transition service – in neurology. In respiratory, I only come in from about the age of 12. A cardiologist may be seen but the cardiac complications are later on. People are slotting in. We are in a co-ordinating role and pull in the specialist services as needed. We are allowed to have this set-up because we have the support.

51. We gathered further evidence of the long distances that patients travel to access specialised neuromuscular services at specialist centres. Dr Nicholas Hart gave an overview of how far people come to the Lane Fox Unit:

We have referrals from Birmingham and Southampton. Although the service stretches down to the south coast, we take patients from many different parts of the country, partly driven by patient choice through GP referral.

52. We had clear evidence that young people are frequently frustrated by over-reliance on family support and care. Stuart Reid told us how he is often forced to rely on his parents for his care:

I need to get extra funding from the local health authorities. Mum or Dad sometimes has to care for me during the night once or twice a week. I don't want to have to rely on them. I want them to be able to get on with their lives. My care assistant was meant to come with me. Dad had to cancel business meetings to come with me today to help me.

53. After hearing about the specialist multi-disciplinary team that is in place at the Lane Fox Unit, this further highlights that young people greatly benefit when all aspects of specialist care and support are put in place. Good practice must be shared and replicated across the country.

**We call on the Government and commissioners to take urgent action to make sure that a named transition co-ordinator is in place for each young person with a neuromuscular condition who is moving from paediatric to adult services. We heard evidence that transition services to provide support to young people when they move from paediatric to adult services are very weak in many parts of the country. (Recommendation 10)**

54. We recognise the need for good links to be established and maintained between a specialist centre and the community, as exemplified by Emily Ballard during her evidence submission:

I have been doing a lot of education with community teams and sharing my skills so that hospice staff, community nurses and community physios

feel confident with the new equipment for these patients and they understand the disease needs.

A community nurse with adults who has not dealt with the disease and doesn't know what to do – if we can support and educate them then they will be able to deal with them in the future rather than saying that the patient should just go to the specialist service and do everything there. There is a huge role for joint work with the community teams and that has been really successful so far.

55. The joint working described here should be developed and implemented across the country. Patients prefer to access integrated services as close to their home as possible – provided they are comprehensive and good quality. This clearly results in financial savings compared with referrals to attend specialist centres some distance away.



Building on the Foundations: The Need for a Specialist Neuromuscular Service for all Patients in the NHS London Region
October 2009



A report by the Muscular Dystrophy Campaign with contributions from and endorsed by the leading neuromuscular clinicians in the London region:

Bart's and the London

- Dr Aleksandar Radunovic, Consultant Neurologist

Dubowitz Neuromuscular Centre: Great Ormond Street Hospital

- Professor Francesco Muntoni, Director and Consultant Paediatric Neurologist
Dr Colin Wallis, Consultant Respiratory Paediatrician
Martin Chainani, Regional Care Advisor

Guy's and St Thomas' Hospital

Evelina Children's Hospital

- Dr Heinz Jungbluth, Consultant Paediatric Neurologist
Dr Elizabeth Wraige, Consultant Paediatric Neurologist

Lane Fox Respiratory Unit

- Dr Craig Davidson, Consultant in Respiratory Medicine
Dr Nick Hart, Director of Research and Consultant in Respiratory Medicine
Emily Ballard, Progressive Neuromuscular Disease Transition Coordinator

King's College Hospital

- Dr Fiona Norwood, Lead Clinician and Consultant Neurologist
Dr Michael Rose, Consultant Neurologist

National Hospital for Neurology and Neurosurgery: University College London Hospital

- Professor Michael G Hanna, Consultant Neurologist
Dr Robin Howard, Consultant Neurologist

Royal Brompton Hospital

- Dr Anita Simonds, Consultant in Respiratory Medicine

In the London region there are two transitional services available to try to rectify this situation. The services occur at Evelina and are jointly run with King's and at Guy's and St. Thomas' with the appointment of a transition coordinator.

Transitional services in KCH are quarterly clinics are held jointly at Evelina Children's Hospital by Heinz Jungbluth and Fiona Norwood or Elizabeth Wraige and Michael Rose. Strong links with Guy's Hospital are extended through Fiona Norwood and a monthly Neurogenetics clinic. In addition a weekly muscle biopsy review meeting is held by Neuropathologists in rotation. This is lead by Neuropathologist Dr S Al-Sarraj with Dr Michael Rose and Dr Fiona Norwood attending.

In November 2008 Emily Ballard was appointed to the new role of progressive neuromuscular disease and transition co-ordinator based at Lane Fox Respiratory Unit and funded through the Trust's charity. The role is designed to provide early respiratory intervention and assessment of patients and as a point of liaison with the adult respiratory unit to detect acute medical changes as patients come through to adult services.

The new position makes communication much easier between physicians and families, supports patients if they need an admission, supports the local hospitals, and provides further support through early symptom management of chest infections etc. The role is also able to address the social needs of patients with neuromuscular diseases and find information on available services and assist young people with career opportunities, social activities and respite care.

However, this role is currently unique and is limited in its geographical scope to the South East region. Other key services still suffer from a piece meal approach, and **additional transition co-ordinator positions need to be established and entrenched** to meet the needs of these vulnerable young people.

*Joint working  
is key*



***Specialist centres can not and  
should not work in isolation***

- We are building links with local hospitals and identifying 'link' consultants
- We share our skills and plan patient care together
- We provide specialist education and support to up skill less experienced staff
- Outreach specialist care effects patient outcome

***Health coordination at the age of transition is essential for patients with DMD***

# ***Our Comprehensive Team***

- Dr Nicholas Hart- Clinical Research Consultant in Respiratory and Neuromuscular Transition service Lead
- Dr Craig Davidson- Consultant Physician in Respiratory and Director LFU
- Dr Adrian Williams- Consultant Physician in Respiratory and Sleep Medicine
- Dr Robin Howard- Consultant Neurologist
- Dr Gerry Carr-white and Dr Stam Kapatzenakis- Consultant Cardiologists
- Natalie Grey- Ward manager (LFU)
- Lucy McGee- Lane Fox Outreach Sister
- Emily Ballard- Specialist Physiotherapist and Transitional Care coordinator (NMD)
- Mr Jonathon Lucas- Consultant Spinal Surgeon
- Mr Kai Lam- Consultant Spinal Surgeon
- Mr Tom Ember- Consultant Spinal Surgeon
- Mr Martin Gough- Consultant Orthopaedic Surgeon
- Mr Fabian Norman Taylor- Consultant Orthopaedic Surgeon
- Dr Heinz Jungbluth- Consultant Paediatric Neurologist
- Dr Elizabeth Wraige- Consultant Paediatric Neurologist
- Jennie Sheehan- Clinical Specialist Physiotherapist
- Rachael Spahr- Specialist Neuromuscular Physiotherapist
- Debbie Clarke- Neurology Outreach Sister

