

Andy Findlay



America - 2001



America 2006

Brief Background information

- **Mis-diagnosis at the age of 12 years**
- **Now recognised that my mother and sister both have FSH.**



Impact of the diagnosis

- The initial reaction was “what do I do now?”
- Only knew about Duchene
- No information given
- After initial shock glad proper diagnosis had been made because it meant that I could now find out more about my condition.
- Condition information was not given by PCT but managed to get this through the MDC.

Impact on Daily Living and Employment

- **No immediate impact on daily living and employment**
- **Gradual impact as time went by**
- **Tried to keep as fit as possible**
- **Further complications added**
- **Mobility problems – wheelchair required**
- **Early retirement**
- **House move**
- **New property adapted**



Impact on Daily Living since 2001

- No longer take it for granted that I can go where I want when I want.**
- I do not know day to day how I am going to feel**
- Loss of driving licence**
- Reliance of other people to take me where I want/need to go**
- Accessibility has to be checked – forward planning**
- Good examples of accessibility which can be shared with others**

Problems with Services

- **Initial problems with accessing necessary services**
- **OT from Social Services assessment**
- **Stairlift installed – later bathroom converted as necessary**
- **Need to be pro-active and to carry out necessary research.**
- **Long delays with processing Disability Living Allowance led to frustration**
- **Attended a meeting regarding an audit tool for assessing services for neurological/neuromuscular conditions.**

Lack of knowledge by Clinicians

- Lack of knowledge about FSH – no follow-up between 1987 and 2001**
- No help with day to day living**
- 2001 more knowledge about the condition.**
- Lack of knowledge by independent doctor when applying for DLA**
- Now a volunteer patient for student examinations**

Treatment – Access to physio and OT support

- Since 2001 have had periods of physio but not for some years and would have to go back for referral from my GP**
- No support from OT at present but can call in as necessary**
- Lack of hydrotherapy provision**

Now the positives - Life as I live it now

- ❖ **Secretary of our local 50+ group**
- ❖ **Generalist adviser for my local Citizens Advice Bureau**
- ❖ **Derby City representative to East Midlands Older Persons Advisory Group (EMOPAG)**
- ❖ **Member of a muscle group for the East Midlands**
- ❖ **Chairman of my Pension Fund**
- ❖ **Was involved with the production of a disability Equality Scheme for the NHS in our region**
- ❖ **Was involved at the planning stage for a new walk-in centre at our local hospital**
- ❖ **On the committee of our local Access Group**
- ❖ **Wrapping Christmas presents for the local market trader's association which raises £1000's for local charities.**

Now the positives - Life as I live it now (continued)

- ❖ **Season ticket holder of Derby County**
- ❖ **Holiday in Florida for a special celebration 2006**
- ❖ **Holidays to Southern Ireland**
- ❖ **Scotland with family many times and again this year**
- ❖ **Edinburgh Festival twice and will go again**
- ❖ **Cruise on the QE2 in September 2007**
- ❖ **Several cruises since QE2 including Panama Canal**
- ❖ **Holidays in the UK with friends and family**
- ❖ **Going to Caribbean in October on biggest cruise ship in the world**

As you will see we try not to let my disability to restrict us too much!

BUT TO BE ABLE TO CARRY ON

- We need access to physiotherapy
- We need continued support through Direct Payments/Individual Budgets
- We need access to services and/or buildings
- **We need a muscle centre in the East Midlands**

The Next Generation



- Two of my three children diagnosed with FSH
- Four grandchildren not tested yet