



## **Muscle Group:** **South West**

*The voice of people with muscle disease – fighting for better services*

### Respite Care Manifesto

**We believe that every family or individual living with muscle disease in the south west region should be offered a minimum of three weeks respite a year as standard across every PCT and local authority.**

#### Why:

1. Respite care and short breaks are essential for the health and quality of life of people living with muscular dystrophy and related neuromuscular conditions. These are complex and progressive conditions which can be severely disabling and life-limiting.
2. We have found that there is a severe shortage of residential respite and short-break accommodation for people with neuromuscular conditions in the south west.
3. While assessment will be necessary for all families to receive the right support, the Muscle Group would argue that a minimum of three weeks respite a year, for people affected by a neuromuscular condition should be adopted as standard across the region.
4. Greater knowledge of the needs of families and adults with a neuromuscular condition will help local authorities and health services to provide timely, suitable and effective respite and short-breaks care. To achieve this, we are calling on each PCT/local authority to have a named individual contact point for respite care who can let families know of their entitlements and signpost them to the support available.
5. Respite and short-breaks are only truly effective for people with a neuromuscular condition when respite homes and hospices are properly equipped for people affected by neuromuscular conditions, and with staff knowledgeable of the often complex needs. This can be achieved by greater training and awareness of neuromuscular conditions among service providers.
6. The Muscle Group feels strongly that they should have a choice of respite care beyond simply staying in hospices for the elderly or terminally ill. Provision must recognise the needs of young adults and those of middle-age and reflect their needs and interests.
7. Respite care cannot simply stop at 18 when young people leave paediatric care, and action should be taken by local authorities and PCTs to develop consistent and comprehensive transition strategies, including the move into respite care for young adults.