



Lyme Disease Action

Carers' Hurdles Workshop Summary

The following slides are the results of the carers' workshop in which carers and family members discussed their difficulties and then priorities.

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Lyme Disease Action

Carers' Hurdles

Carers were wives, husbands, partners, sisters, fathers, mothers and grandmothers

- Financial strain
 - Huge sums for private treatment when NHS fails
 - The patient is often out of work and their salary lost
 - If the patient is a child or very ill then the carer often gives up work
 - Impossible to budget
- Physical strain
 - Taking more of the (increased) domestic workload
 - Worry; interrupted sleep; tiredness
 - Still having to manage at work

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Carers' Hurdles

- Emotional strain
 - sometimes dealing with personality changes
 - having to guess how the patient feels
 - Deterioration in social life
 - Feeling of guilt – do we understand? Do we do enough?
 - Explaining to children and relatives who cannot see evidence of illness
 - Everything takes longer to do and you can't do everything together: complete change in lifestyle
 - Have to maintain equilibrium despite tiredness
 - Luck of the draw whether you have a good GP and maybe doing battle here as well

3



Lyme Disease Action

Carers' Priorities

- Increase public awareness of dangers and symptoms
- Increase medical profession awareness
- Primary school awareness – children will influence parents
- Use vets to spread the word
- Work to make the long term use of antibiotics for Lyme disease accepted
- Do not knock the NHS as it is important that recognition of, and treatment for, Lyme disease becomes available
- We need advice on how to handle/persuade the doctors
- Get the Scottish laboratory to influence Southampton
- Support and recognition of what carers go through and what they do

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