

MUSCULAR DYSTROPHY

EMOTIONAL RESPONSES

MD

- Similarities and Differences
- Effects on individual and others
- Issues re diagnosis
- Grief and loss

SIMILARITIES

- Progressive
- Selective
- Weakness
- Degeneration
of voluntary muscles

DIFFERENCES

- MD related
 - *age of onset
 - *muscles involved
 - *rate of progress
 - *other systems involved
 - *family history

MD RELATED DIFFERENCES

- Continuum of mild MD with slow progression over a normal life span to death in infancy

DIFFERENCES

- Differences exist
 - *within the disease
 - *between diseases

With different degrees of

- *mobility
- *independence
- *carer needs

OTHER SYSTEMS INVOLVED

- *heart
- *GIT
- *nervous system
- *endocrine system
- *skin
- *eyes

DIFFERENCES IN FAMILY FACTORS

- * GENETIC CAUSES

Genetic causes are common

eg 2/3 DMD inherited X-linked recessive

There are emotional implications for:

the person

the siblings

the parents and extended family

DIFFERENCES NOT RELATED TO MD

- Individual's experiences and expectations
- Emotional fabric
- Social context- family/ friends/ support
- Intercurrent issues – disease is a part of life and does not define life

DIFFERENCES NOT RELATED TO MD

- Person has an influence on and is influenced by their
- Environment
 - house – alone/shared/supprted
 - community-school/uni/work/neighbours
 - relationships-family/friends/sexual

IMPACT OF DIAGNOSIS

- When uncertainty becomes certainty BUT the disease is
 - irreversible
 - untreatable
 - progressive

IMPACT OF DIAGNOSIS

* person: distress-----relief
grief

- family : “carrier”
siblings

all family members re potential
care requirements/roles/relationships and
expectations

GRIEF

- Phases :
 - denial
 - anger
 - bargaining
 - depression
 - acceptance
- Precipitants

GRIEF

- *recurrent theme
 - progressive nature of the disease
 - ongoing losses

CHALLENGES

- *maintaining a sense of realism and optimism
- *dealing with well meaning but often ill informed advice from others
- *the change in personal relationships for the person (frustration and guilt) and their carer(s) tiredness/social , recreational ,and occupational changes/depression

