

Finding a way: Parenting facing Myotonic Dystrophy

I did expect he would be able to do things
I just thought he couldn't be bothered,
this snoring lump by the side of me,
who wouldn't get involved with our baby,
who didn't want to try

"I'm so tired,
I've got myotonic dystrophy.
I don't want to talk about it
Can't do this,
I've got myotonic
I don't want to talk about it.
If I don't talk about it, it's not real."

Your family, they want better for you:
"He should be doing this, he should be doing that!
He's got no motivation,
He's being lazy.
He needs to get involved more.
He doesn't help you.
We don't know why you stay with him. "

Trying to justify to them,
"He's my husband, he's not well."
In the back of your mind you think,
"Well yes,
Why do I put up with it?
Why do I tolerate it?
Why do I do everything?"

Trying to encourage him to do more,
nagging, you keep asking.
He wouldn't do it.
Tired, upset, you stomp around the house,
do everything yourself

It took a long while to understand, to make him understand
I couldn't possibly do everything.
It's hard enough when you've got two fit parents, you know

Until,
he really admitted to me he couldn't do it:
"I can't,
It's too hard,
I don't have the strength,
I don't have the power in my body
If I can't do what I'm supposed to do,
why should I bother helping at all?"

You have to be a bit more physically stronger than your child,
to stop her running riot.
If you're walking along the street there's cars.
You say, "Hold my hand."
She'll hold it for a little while,
then she'll try and pull away from you,
like all kids do.
I've got to hold on to her, until she gives up the fight sort of thing
He's frightened of hurting her,
holding her too tightly.
Once he got hold of her really tightly he wouldn't be able to let go,
he can't release the grip
Knowing what today's society is like, he'd probably be hauled off,
down to social services

Finding a way of letting him do what he can do,
it's just a way of life now,
he can't do anything to change the fact that he's got myotonic dystrophy,
but he can not let it take over his life

He's accepting now,
living his life now,
doing everything that he can.
Now he's actually willing
he's got a bit more spark of life in him
I've got some of the old person back
I don't mother him quite as much as I did, you know

He will start something,
will do it so far,
then he'll say,
"Can you just finish it off, for me?"
I don't mind that,
he's making the effort
If I don't think that he's being fair to me, I tell him.
I listen to him, he listens to me

We talk about our daughter starting school next year:
"At sports day you'll have to do all the parent and child races,
I won't be able to."
She's learning that daddy can't do certain things
why daddy doesn't
why daddy can't

Now my family can understand why he can't, that he isn't lazy
I don't feel like I'm being pulled from both sides.
It makes it so much nicer,
now it's a family thing.

Claudia Downing, is completing a Postdoctoral Fellowship at the Centre for Family Research, University of Cambridge funded by the Wellcome Trust, under their in Biomedical Ethics initiative, (Award Reference: 065207, 2002-2005)

Parenting in the space between health and illness: a comparative study of ethical dilemmas arising from the certain knowledge of a gene positive status for Huntington's disease and Myotonic Dystrophy