

**ONLINE SUPPLEMENT Combining creative writing and narrative analysis to deliver new insights  
into the impact of pulmonary hypertension**

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### **Getting On With It**

Sonia is good at many things. But if there's one thing that you had to pick, one thing that she's really good at, it's talking. Especially about herself. She loves it. She's pretty good at it too.

She's got the right profession for it as well, she's a teacher. Not originally what she intended to do into but it's where she ended up. Lucky for her and the school. They were pretty keen to keep hold of her once she started; she likes to make lessons interesting, different, relevant. She uses what she knows, she uses her own experiences.

All that talking allows a bit of reflection, allows a bit of time to consider what's going on, consider what's going to happen. And consider how to react to it all.

That's the latest lesson for the kids. Life's tough. Life can be very difficult. But sometimes you just have to get on with it. Learn from it.

And that's what Sonia has been talking about with them recently. They're naturally inquisitive, they naturally want to ask. They don't have the same inhibitions that adults might have. Sonia passes on what she knows, tells them what she's learnt in the months she's been away from school.

They want to know, there's plenty to teach them. And Sonia does like talking.

## Reactions

Living with long term health problems is something that no one really considers, no one really understands until it happens. To have this but with a disease that no one has ever heard of makes it so much more complex. Understanding the issues that go along with it almost impossible for someone else.

Yet what has amazed me consistently is how something that could inspire such self-centeredness and self-pity can do exactly the opposite.

I listen as Rob talks about his friends. They're worried about him, he can see that. They're worried about the future, what's going to happen with this unpredictable disease. His friends aren't used to dealing with mortality at their age.

But Rob also worries about his friends, worries about their concerns and how they will deal with them. He worries over their concerns about whether they'll be attending his funeral. As he covers the long distance to the specialist centre he worries for them.

It makes you reflect. On yourself, on those around you. Could I show such concern for others? With everything else going on? With so many things to think about day to day that others wouldn't even consider. Things that don't even cross people's minds.

It's just one of the many examples of how people's reactions can be so different from what's expected. So different from what they could so easily be.

## **Water Baby**

Jenny has developed a special name for the oedema that collects around her middle - she refers to it as her water-baby. When first meeting her, if you didn't know better, you could easily be mistaken for thinking that she was about to have a child, although her distended belly contrasts sharply to the rest of her slim frame. It's always hard to tell when a person is wearing pyjamas and a dressing gown, but Jenny doesn't look like she has a lot of extra padding to spare.

Except around her middle. She jokes with her young son about her water-baby and he asks her if she is going to have another child. She laughs this off with a no. His next question follows the infallible logic of a young boy, "Then you've just drunk a lot of water then, Mummy". You cannot deny a child their thought process - it's all in the name. If it's not a baby, then the only other option is water and, to a child, there is only one way that water gets into the body.

For Jenny, however, this water-baby means another trip to the hospital and more time away from her son. But a funny name and a positive attitude make all the difference, especially when you are trying to raise a child whilst dealing with an illness. By giving the oedema a name that a young boy can relate to means he is able to talk about it, on his level, with his mum. They still have that communication and connection about something that has been life changing for the whole family. I wonder what he will think when he looks back at the memory of his mum's water-baby when he is older. Will he still think of it as her water-baby?

## **“Well, this don’t seem right!”**

“Well, this don’t seem right!” Harry thought to himself as he walked to the station. He knew he was unfit but this just didn’t seem right. All this breathlessness? It’s only a 10 minute walk. Maybe he should speak to that doctor again, see what he thinks.

“Well, that’s not quite normal!” Harry heard from the doctor. Funny how even someone he was seeing for his legs noticed his breathing. Harry thought to himself that he must mention it to the other doctor again. His breathing was getting a bit worse.

“Well, that’s unusual!” from a different doctor this time. Apparently one side of his heart isn’t doing so well, but it’s strange, normally it’s the other side of the heart that goes wrong. Someone’s got to be different, Harry thought.

“Well, I think I’ll refer you on,” a doctor from a different department. He wondered to himself as he made his way home on the bus how he would get to this new hospital. It was a bit further away and he couldn’t drive the distance any more, it was a bit too far. He’d talk to his sister, she if she was free.

“Well, we’ve got the results back.” Not a disease that Harry had heard of before. But he understood what had gone wrong, understood what he needed to do. A long journey to get there though. And it isn’t quite finished yet.