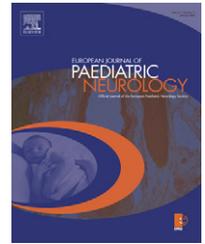




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Original clinical historical contribution: Stuart Green Vignettes

Stuart Green's Vignettes 7 and 8

1. Do not tell our daughter

A 12-year-old girl was diagnosed because of a progressive weakness with a condition known as Friedreich's ataxia, a progressive condition causing weakness, unsteadiness and inco-ordination with a chance of developing a cardiomyopathy (a weakness of the heart muscle). When discussing the diagnosis with the parents, I asked what they had told the young girl, who was a bright kid at a Grammar School. They said they had told her nothing at all after all it would be totally inappropriate to tell a 12-year old she had "a terrible condition which was going to shorten her life", I explained to them that the 12 year old was already having physiotherapy, she knew she had a problem; she was having blood tests and imaging and what was it they thought she thought she had? They told us she thought she just had some form of un-coordination and that was all they wanted her to know. I said to them it was important that she should know something about her condition but they felt this was entirely inappropriate and absolutely refused to countenance it even though I said she might "learn this from somebody at school or a physiotherapist". They were quite distressed by my suggestion that she should be told anything about her condition although at the age of 12 years she could easily find out things for herself on the Internet, and must be asking questions about why she was still having various blood tests. When I saw them a few months later they said they had reluctantly told her that she had Friedreich's ataxia but not told her anything about it (assuming she would not ask). They were very reluctant to discuss the condition at all with her in anyway and I said it was difficult to engage the girl in any form of management or therapy if she did not know what she had. I then told them there was a trial of a particular drug, a vitamin supplement, going on in London, which might possibly be of benefit in her condition, thinking they would be delighted with this. I was wrong. They were aghast. The told me "Not only have you upset us by insisting, we tell our daughter about the diagnosis of Friedreich's ataxia but now you want to use her as a guinea pig. We are very disappointed".

You cannot please everybody!

Comment

Communicating a diagnosis, particularly one with such dire implications, is one of the most painful thing that we child neurologists have to do, and possibly one reason why some paediatricians avoid this specialty. We have never been taught how to do it, if there are better ways, how it affects us. What we have learned comes from some older compassionate mentors or from our errors rather than from the (rare) professional psychological or psychiatric literature. This story illustrates the complexity of the process, the partners being involved in an always unique constellation. What is not told in the story but is implicit, is that communicating a diagnosis is only the beginning of a dialogue, a dialogue that one hopes will change from the unavoidable bitter feelings and aggression toward us to an attitude that can foster our continuing empathic support and help. But the families and ourselves the paediatric neurologists also have to be emotionally helped.

2. All is not what it seems

Many years ago, when I was training, I met a young man who presented with a dense right-sided weakness. We thought it was due to a stroke. In those days, we did not have CT or MRI scans and an angiogram was something not undertaken lightly. He seemed otherwise well. He was not acutely ill and we wondered what the probable cause of the stroke was. He was a simple farm lad and it was difficult for him to explain articulately how it had happened. It eventuated that he had been found in a hayrick, collapsed, by another farmhand in what one might call a compromising situation. We began to suspect all was not what it seemed. When we asked him to walk he did so with a pronounced limp and his arm did not swing. However, there was just something about him that prompted me to ask the next question. "John" I said "have you always walked like that?" and he said without batting an eyelid "No, not at all, I used to walk like this!" In the flash of a second, he walked ten paces across the room perfectly normally and then said "But now I can't do that any more

and I walk like this” and walked back again with his right leg paralysed! The moral is it is best not to be caught in compromising situations, otherwise you may get an angiogram.

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