

UNIT 5: TO HAVE A BABY, OR NOT TO HAVE A BABY? - THAT IS THE QUESTION

TEACHERS' NOTES UNIT 5

TO HAVE A BABY, OR NOT TO HAVE A BABY? -THAT IS THE QUESTION

OBJECTIVES

To think about the pleasures and responsibilities of parenting.

To show how genetic conditions can affect reproductive choice.

SUGGESTED AGE RANGE

14-16 year olds.

CURRICULUM LINKS

For use in English, PSE, Parenting/child development, Social studies, Moral education etc

SUMMARY OF CONTENT

Students brainstorm the pleasures and hard work involved in caring for babies and young children before being asked to draft a response to a letter from a young man with Charcot-Marie-Tooth disease (CMT), an inherited neurological condition. In his letter, Peter asks whether he and his fiancée are being irresponsible if they decide to try for children knowing that each child of theirs has a 50% chance of inheriting CMT.

TEACHERS PLEASE NOTE

Activity Sheet I focuses on Peter, a young man with a genetic condition called CMT. In order to understand Peter's dilemma, it is necessary to know that the type of CMT which Peter has (Type 1a) is caused by a faulty dominant gene. This means that each and every child of his stands a 50% chance of inheriting the faulty gene and being affected by CMT.

You might find it useful before the lesson to read through

Activity Sheet I: Peter's letter, the Genetic Condition Card Charcot-Marie-Tooth Disease (CMT), and the Information Sheet: More about...Peter and CMT.

It is important to be aware of the fact that some students in the class may themselves have a genetic condition, or be a carrier, or have relative who is affected. Sensitivity is required to avoid putting such students under stress.

MATERIALS NEEDED

Each pair of students will need one copy of the following:

Activity Sheet I: Peter's letter.

Additional information includes:

Genetic Condition Card: Charcot-Marie-Tooth Disease (CMT)

Information Sheet: More about...Peter and CMT. [N.B. If your students have good reading skills, photocopy and hand out these additional pieces of information for students to read through themselves. If literacy levels are low, however, you might prefer to read through the additional information yourself and verbally feed in any details you think will help students write their response to Peter.]

WHAT YOU DO

Explain that the purpose of today's lesson is to start by thinking about what it is like to be a parent and then go on to explore how the decision to have a child can be affected by knowing that one could pass on a genetic disorder to that child.

As a whole class, ask students to raise their hands if they have ever:

TEACHERS' NOTES UNIT 5

WHAT YOU DO continued

- a) Read to a young child
- b) Changed a nappy
- c) Helped to bathe a baby
- d) Pushed a buggy or pram.

Acknowledge that looking after babies and young children can be both fun and hard work. Then ask students to brainstorm all the words which come to mind when they hear the words 'babies' or 'children'. Accept all contributions without comment and record them on a board or flipchart.

- Ask students to get into pairs. Then ask them to draw a line down the middle of a piece of paper. The left column is for positive/fun things associated with babies or children, and the right column is for negative/unpleasant things. Ask students to look at all the words on the board and decide which column they want to put them in. If they are not sure or cannot agree, they can put a word across the middle of the two columns.
- When they have finished, discuss the contents of each column as a whole class.
- Which column has more words in it? Why do students think this is?
- Do students think the columns would look different if parents were asked to do the activity? What sort of things make being a parent easier? (money? a satisfying job? somewhere to live? a caring partner/ support from family or friends? financial and practical support if parents and/or their children have a disability or special needs?) What sort of things make being a parent harder?

Give each pair of students a copy of Activity Sheet 1

Peter's letter and read it through with the whole class. If students are able readers, give each pair a copy of Genetic Condition Card: Charcot-Marie-Tooth Disease (CMT) and the Information Sheet: More about...Peter and CMT to read through for additional background information. Be prepared to verbally summarise the information they contain for less able readers.

Check that everyone has understood the content of the Genetic Condition Card and Information Sheet by asking students to briefly summarise:

- what CMT is and how it affects people
- how Peter's life has been affected by having CMT.

Possible answers to (b) for teacher reference:

In the Information Sheet, Peter talks about CMT affecting him as a child in the following ways:

- He had a painful electrical test when he was 4 to diagnose the condition.
- He had trouble keeping up with the other children when he walked home from school.
- He had operations on both feet when he was about 7.
- He couldn't run or participate in sports.
- Some children were quite cruel towards him and called him names.

In the Information Sheet, Peter talks about CMT affecting him as a young adult in the following ways:

- He worries about what other operations he might need in the future.
- He is not sure whether or not he should have a child when each child of his has a 50% chance of being affected by CMT.
- He gets a free car and housing benefit because he is disabled.
- He has made some friends through having CMT.

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Then ask students either individually or in their pairs to draft a reply to Peter's letter. In their letters, students need to:

1. Show that they understand the dilemma Peter faces
2. Give their opinion about whether or not they think Peter and his fiancée should have children
3. Explain the reasons behind their opinion.

Set a time limit for students to write their replies.

[N.B. It is important to be aware that pupils may have experienced something in their own lives which gives them a special insight into Peter's dilemma. Make it clear that pupils are welcome to use this experience to help them draft their reply, but only if it feels comfortable for them to do so and if they are happy for other people to read what they have written.]

If there is time at the end of the lesson, you might like to select some letters to read out. You might also wish to discuss whether students would have responded differently if it had been a woman (e.g. Peter's fiancée) who had the genetic condition. Do students feel that deciding whether or not to have children is more difficult for the person with the condition or their unaffected partner?

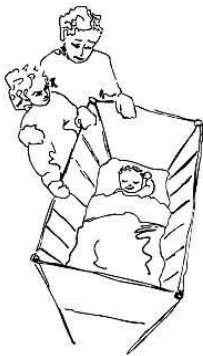
Students could also be asked to finish one or more of the following sentences anonymously on a separate piece of paper:

- I would/ would not like to have children unless...
- I would/ would not like to have children if...
- I would/ would not like to have children because...

Letters to Peter and completed sentences could then be displayed around the room for students to read and comment on.

STUDENTS' ACTIVITY UNIT 5: SHEET 1

TO HAVE A BABY OR NOT TO HAVE A BABY – THAT IS THE QUESTION



PETER'S LETTER

This letter first appeared in ComMenT, the newsletter of CMT International UK. The writer is a young man with Charcot-Marie-Tooth Disease (CMT).

'Hi. My name is Peter and I am 21 years old. I was first diagnosed as having Charcot-Marie-Tooth Disease (also known as Peroneal Muscular Atrophy, or more recently Hereditary Motor and Sensory Neuropathy) at the age of four. They tell me now I have Type 1a, whatever difference that may make. I guess I was one of the lucky ones, having always known what it was that made me walk funny.

When I was just a kid, I thought by the time I have my own children there will be a cure. Well, as fast as medicine is moving, there is still no known way to prevent it from being passed on to my children and it doesn't look like there will be for at least the next ten years (please correct me if I'm wrong).

I often wondered over the years whether it would be right to have my own kids. There is a 50% chance of passing on CMT, although down my father's line it has affected 100%. Should I take the chance or not? My condition is comparatively mild although I have had operations on my feet, hip, and more recently a spinal fusion. Is it fair to put my child at risk of those same operations or maybe worse? Will my child be among the 50% that are supposed to be okay? Well there is no way of answering that last question, but I'm sure I'm not alone in asking this. My fiancée thinks it is irresponsible to bring a disabled child into the world. Maybe she is right. Is the risk of disability too great to contemplate having a child? I have come to the conclusion that I would be prepared to take that chance, but am I being cruel to my child to threaten its mobility and risk numerous operations?

I would very much appreciate your opinions and/or advice on the matter. Also if you know people who are less able than others, please let me know what their views are. Do they regret being born because of their disability? Do they resent their parents for having them? Or are they just glad to be here? Please drop me a line. I look forward to hearing from you.' Peter

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What would your advice be to Peter and why? Reply to his letter giving your views.

Everyone with CMT is different

If Peter were to have a child with CMT, that child might not be affected in the same way as him. Also developments in scientific knowledge and health care could change things for everyone in the future

STUDENTS' ACTIVITY UNIT 5: MORE ABOUT PETER AND CMT

Q. Tell me about CMT.

Well it affects the peripheral nervous system. Basically, it reduces the effectiveness of the nerves to conduct electrical messages to and from the brain to various parts of the body like the foot, lower leg, hand and forearm. Because the nerves don't give the right messages, it makes the muscles weaker. I have it in my left hand and slightly in my right. I'm quite mildly affected, but CMT can weaken the muscles in the feet and legs enough for a person to need to use a wheelchair.

Q. When and how did you find out that you had CMT?

When I was four years old, I had some electrical tests done which test the speed with which the nerves conduct messages. I can still remember it because it was very painful. They put electrodes all over your body and they pass current through it and if they don't get much reaction they turn the current up a bit so it's like passing little electric shocks up and down your body all the time.

Q. Did you go for these tests because there was CMT in your family and someone suspected it?

Well it was more by chance actually. My dad has CMT but he had been wrongly diagnosed and told he had various different things, most of which would have killed him by now! In fact misdiagnosis of CMT is quite a common problem because lots of doctors haven't got a clue about it. Anyway my mum had worked in an orthopaedic hospital and doctors there saw me walk and said they were pretty sure that it was CMT.

Q. Was walking the only problem?

It was at the time, yeah. I had trouble keeping up with the other kids walking home from school and that sort of thing.

Q. Have you had other problems since?

Well, when I was about 7, I had operations on my feet to release the tendons and that helped straighten both feet out at the time. Then in about '88 I had my right hip socket rebuilt because it had disintegrated (not because of CMT but because I was walking badly on it or something...) And then in '93 I had spinal fusion to help straighten out my spine.

Q. What was that like?

For 3 or 4 months afterwards it was difficult because they break your back basically so you're laid up most of the time and it's quite uncomfortable to start with. But now I wouldn't know I'd had it done except perhaps my back isn't quite as flexible as other people's. Before the operation I had a 50 degree curve in my spine but they straightened that out to virtually nothing which has made sitting more comfortable for me. My brother, who also has CMT, had a 120 degree curve in his spine. They haven't been able to fix it quite so well because it was worse than mine. He's had nine operations...

Q. Does it make it easier having other people in the family who are affected?

I suppose it's easier in a way because you're not the only one. My dad has CMT as well (although he was diagnosed after I was) so I grew up seeing him walking on sticks and crutches and stuff and I'm used to it really. It was part of our lives as a family. I was never shocked about having CMT because it's always been there.

Q. What effect does CMT have on your life now? Are there any things you can't do that you would like to do?

I'd like to be able to run which I can't do, although I'm not so worried now about that as I was when I was at school.

Q. So did you do sport at school?

Not really, no. I quite like sports but I just can't participate in them. I did try but it was quite distressing sometimes.

Q. Did other children give you a hard time?

Yeah, some of them were quite cruel. You get called names like 'cripple' and 'spaz'. After a while you get used to it and push it under the carpet but initially it was quite difficult.

Q. Do you see yourself as disabled?

No I don't really. I mean, I drive an ordinary car and basically do most of the things that other people do.

Q. What's the worst thing for you now about having CMT as a young adult?

I suppose the main thing is the possible risk of passing it onto my children, and if I do have children, whether or not to test to find out if they also have CMT. Initially I think it would be quite distressing to find out that we had given our child a disability. Then there's always the thing in the back of your mind about whether your CMT is going to get worse or not and how many operations you're going to have in your lifetime....

STUDENTS' ACTIVITY UNIT 5: MORE ABOUT PETER AND CMT

Q. Has it got worse?

I don't use sticks or any other special equipment at the moment and I don't think I'll ever be a wheelchair user. But my right foot is going to need surgery probably in the next 18 months. I haven't done anything about it yet but I don't think it's a good idea to put it off for much longer.

Q. Are there any good things about having CMT?

Well, it used to get me out of sports day at school! I've also met quite a lot of people as a result of it and made a few friends. And because I'm registered disabled I get a free car and housing benefit.

Q. What are your hopes for the future?

Just the normal things really like a stable relationship, a job, nice family, that sort of thing.

