Creating patient information leaflets on mitochondrial diseases for adult patients

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Introduction

Mitochondrial disease is an umbrella term for a range of diseases caused by a dysfunctional mitochondria. Due to the complexity of the disease and the lack of awareness, it has been difficult to create accessible information for patients with mitochondrial disease. This is something to be addressed about because patients need to understand the information in order to make informed decisions . Some patients also experience anxiety due to lack of information, which would impede their recover[1]. Although there are a few charities addressing this problem in children, most notably the Lily Foundation, there is significantly less information targeted to adults. **The majority of mitochondrial patients at the Newcastle Mitochondrial Clinic are adults and are the target audience for the leaflets we created.**

This is an ongoing project and the aim at the end is to produce a well-written and effective information leaflet that can be distributed to the patients at the Mitochondrial Clinic.

Aims

1. To better understand how to effectively communicate information on mitochondrial diseases to patients and the general public

2. To create an accurate and accessible patient information leaflet that can be used as a template for future patient information leaflets

Method

1. **Evaluation of current and available information.** An analysis was carried out comparing the information contents of several mitochondrial disease websites, including the Wellcome Trust's own. Several aspects were examined, including the relevance of the information and how the information was delivered.

2. **Creating the leaflet.** Using conclusions from the analysis, the author set out to create a draft leaflet on single large-scale deletions, using literature.

3. **Review by health professionals.** Before piloting it out to the patients and the public, the leaflet was sent to some health professionals within the mitochondria clinic.

4. **Piloting the leaflet to patients and public.** The draft leaflet was sent out to a patient focus group and VoiceNORTH, along with a questionnaire to evaluate it.

References

1. Glaser R. and Kiecolt-Glaser JK. 2005. Stress-induced immune dysfunction: implications for health. *Nature Reviews Immunology*. 5. pp243-251

Results

1. Evaluation of current and available information: Too much jargon leading to readability issues, font size too small, misleading information, lack of diagrams, relevance of information and difficulty navigating around the information.

2. The leaflet created is shown in figures 1 and 2

3. Pilot leaflet was sent to 9 health professionals, including a GP from Australia. Some of the comments included simplifying some sections and adding diagrams.

4. The leaflet has been sent to patients for feedback and replies are pending.

Conclusions

The most important aspect of providing information for patients is to help reassure them about the prognosis of their disease. It was important that the information was written in a manner that emphasised hopes of recovering, without sacrificing accuracy. Observations from some of the patients show that anxiety regarding the disease can be debilitating, even more so because of how little known mitochondrial diseases are.

The second aspect highlighted is assuming patients understand commonly-used scientific terms such as 'gene' and 'DNA'. As these are difficult to explain in words, we thought diagrams would be the best way to clearly explain them (figure 3).

Sending the leaflets to patients would give us a better indicator of the effectiveness of our leaflets and would be the next best step with this project.

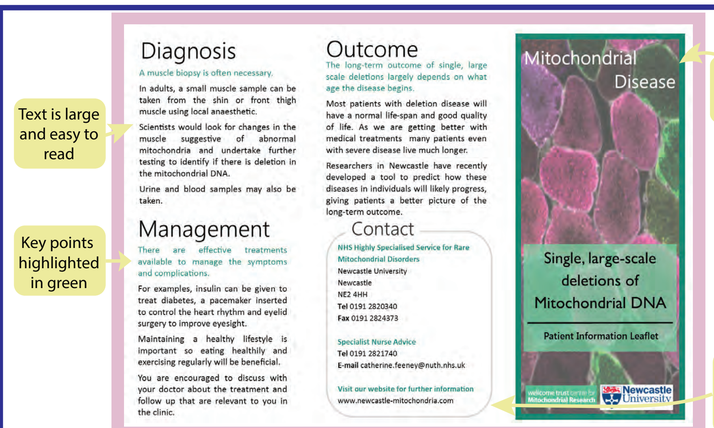

Figure 1 Front cover of the single large-scale deletion leaflet

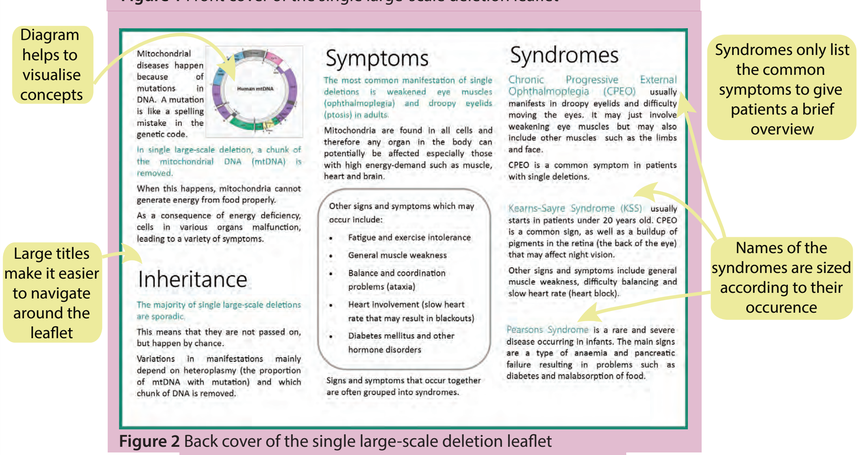

Figure 2 Back cover of the single large-scale deletion leaflet

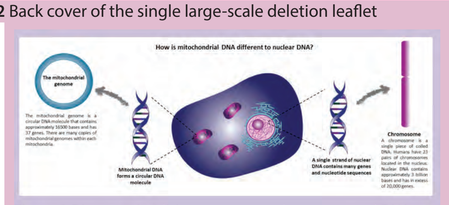

Figure 3 Diagram visualising concepts such as genes and DNA