

“When do I tell my family, what do I tell them?”

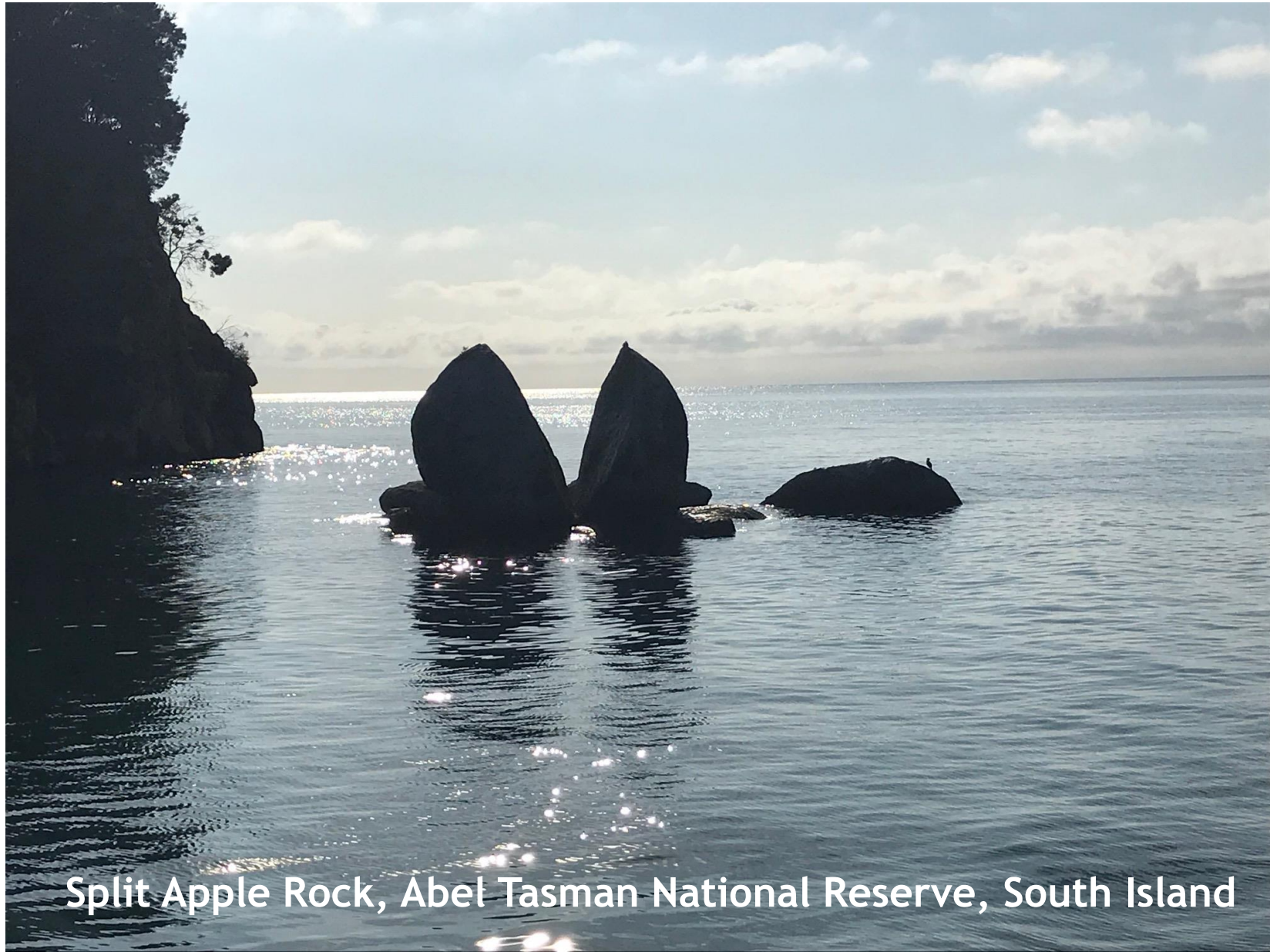
The importance of psychological adaptation to a genetic diagnosis before patients are able to share information about their diagnosis

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Split Apple Rock, Abel Tasman National Reserve, South Island

The Family Web Study



Family
Web

Aim

- ▶ Investigation of whether sharing digital documents online could help patients share information about their diagnosis with their relatives.

Methods

- ▶ Cross sectional survey (n=286)
- ▶ Semi-structured telephone interviews (n=14)
- ▶ Think Aloud interviews (n=12)

Participants were all at high risk of bowel cancer and were aware that their diagnosis had implications for their relatives.

Results

Interview data revealed 4 major themes

Factors influencing patients' ability to share information:

- ▶ Impact of the diagnosis
- ▶ Access to practical information about the diagnosis
- ▶ Appropriate methods of communication with relatives
- ▶ Psychological adaptation/ adjustment to the diagnosis

Results

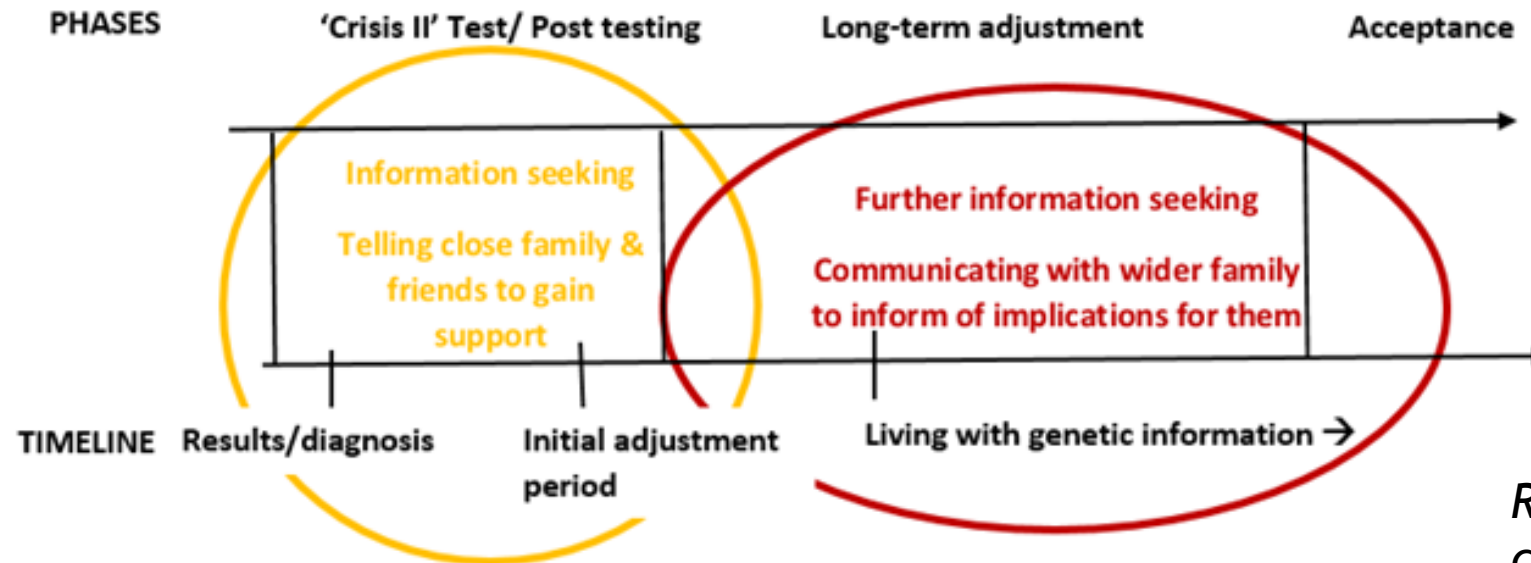
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Phases of adjustment

(modified from Rolland & Williams Family System Genetic Illness model)



Red circle shows where communication happens with the wider family after an initial period of adjustment.

Rolland, J.S. and J.K. Williams, *Toward a Biopsychosocial Model for 21st-Century Genetics*. Family Process, 2005. 44(1): p. 3-24.

Implications for practice

- ▶ Patients have to adjust to the knowledge of their diagnosis before they can share information with their relatives.
- ▶ **Follow-up** and ongoing contact would assist patients in their own adaptation and give them practical support when communicating with their relatives.

▶ www.familyweb.org.uk



Family
Web



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All the patients who participated