

G.2.1.3 Issues identified in Huntington's disease

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
Barrier/facilitator – Information provision							
1 (Bisson)	Interviews	Some confusion was apparent among people with Huntington's disease regarding what advance decisions and powers of attorney are, not least the difference between advance decisions and euthanasia.	Not serious	Moderate ¹	High	Moderate ²	Low
1 (Bisson)	Interviews	Easy-to-follow, consistent verbal and written information was desired, which should be Huntington's disease specific.	Not serious	Moderate ¹	High	Moderate ²	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
1 (Bisson)	Interviews	Involvement in the care pathway was a positive experience for the majority.	Not serious	Moderate ¹	High	Moderate ²	Low
Facilitator – Therapeutic relationships							
1 (Bisson)	Interviews	A facilitator for advance planning is having an established therapeutic relationship with an expert in Huntington’s disease. Personal qualities such as being approachable, caring and sensitive with good communication skills were felt to be important. Participants also recommended the additional offer of home visits by a Huntington’s disease Association Advisor.	Not serious	Moderate ¹	High	Moderate ²	Low
Facilitator - Early introduction to advance decisions							
1 (Bisson)	Interviews	Opinions of patients with Huntington’s disease were different to professionals. Professionals were reluctant to approach service users too early, particularly asymptomatic individuals with the altered Huntington’s disease gene, for fear of causing distress.	Not serious	Moderate ¹	High	Moderate ²	Low
1 (Bisson)	Interviews	The earlier discussions regarding advance decisions are introduced the better, subject to checking personal circumstances and support, to allow consideration of them before individuals develop symptoms or their symptoms worsen.	Not serious	Moderate ¹	High	Moderate ²	Low
1 (Bisson)	Interviews	It was considered important to have a minimum 2-week “cool off” period between an initial meeting and advance decision completion. The duration should be flexible allowing for as many sessions required to reach a decision.	Not serious	Moderate ¹	High	Moderate ²	Low
Facilitator - Advance decision forms							
1 (Bisson)	Interviews	The main issues that people believed should be on the form were: life-saving treatments, percutaneous endoscopic gastrostomy feeding, location of future care,	Not serious	Moderate ¹	High	Moderate ²	Low

Studies	Study design	Description	Methodological limitations	Relevance	Coherence	Adequacy	Confidence
		capacity assessment, witness details and a distribution list. A summary sheet for patient files and checklists for education, completion and review were considered important. Participants suggested adding statements concerning organ donation and whether independent legal advice had been received.					
Facilitator – Power of attorney							
1 (Bisson)	Interviews	The power of attorney information was considered to be too detailed to be included on the advance decision form. Therefore, a single booklet containing all the information was recommended.	Not serious	Moderate ¹	High	Moderate ²	Low
<ol style="list-style-type: none"> Some people in the study were positive for the Huntington's disease gene but did not yet have a diagnosis of Huntington's disease Insufficient data to develop a full understanding of the phenomenon of interest 							