

## Appendix 1- Key themes and their relationship to the codebook

### Codebook

Parent Codes	Associated child codes
Affect of Life	Difference in identity, domestic chores, environment, family and friends, financial, impact on relationship, living with uncertainty, limitations on social life, loss of independence, self-care, social interaction, work
Barriers to getting support	Denial, embarrassment, funding, geography, ignorance of what's out there, internet related, intrusion on life, time.
Being a carer	Impact on self, preserving independence
Disease progression	Finding out about SPMS, future deterioration, RRMS descriptions, SPMS descriptions, what current stage means
Health Care Experiences	Confidence in the service, infrequency of contact, neurologist consulting style, nurse consulting style, understanding the purpose of appointments, ways to improve care and support
Keeping Active	(N/A)
Perception of MS	Embarrassment about disease, future cure, hope for improvement.
Services used or available	District nurse, GP, internet, local patient groups, MS charities, MS nurses, neurologist, occupational therapists, physiotherapy, social services.
Support	Finding support, group support, need for support, one-to-one support, preferred format, support offered to carers.
Symptoms	Cognition, continence, fatigue, hardest for carers to deal with, mobility, mood, pain, unpredictability, variability between patients, vision.
Wanting to help others	(N/A)

### Key themes and the parent and child codes they were derived from

Key theme	Parent codes	Associated child codes
Realisation – Finding out about progression	Disease progression Barriers to getting support Support	Finding out about SPMS Denial Need for support, preferred format
Reaction – What progressive disease means	Affect on life Barriers to getting support Disease progression	Difference in identity Denial Finding out about SPMS, Future

		deterioration, RRMS descriptions, SPMS descriptions, what current stage means
	Support	Need for support, preferred format
Reality – Living with progressive disease	Affect of Life	Difference in identity, domestic chores, environment, family and friends, financial, impact on relationship, living with uncertainty, limitations on social life, loss of independence, self-care, social interaction, work
	Being a carer	Impact on self
	Keeping active	N/A
	Support	Finding support, group support, need for support, preferred format.
	Symptoms	Cognition, continence, fatigue, hardest for carers to deal with, mobility, mood, pain, unpredictability, variability between patients, vision
Reality – Healthcare experiences around transition	Barriers to getting support	Funding, geography, ignorance of what's out there
	Health Care Experiences	Confidence in the service, infrequency of contact, neurologist consulting style, nurse consulting style, understanding the purpose of appointments, ways to improve care and support
	Services used or available	District nurse, GP, internet, local patient groups, MS charities, MS nurses, neurologist, occupational therapists, physiotherapy, social services.
	Support	Support offered to carers
Recognising future challenges-hopes for the future	Affect on life	Living with uncertainty
	Being a carer	Impact on self, preserving independence
	Disease progression	Future deterioration
	Perception of MS	Future cure, hope for improvement.