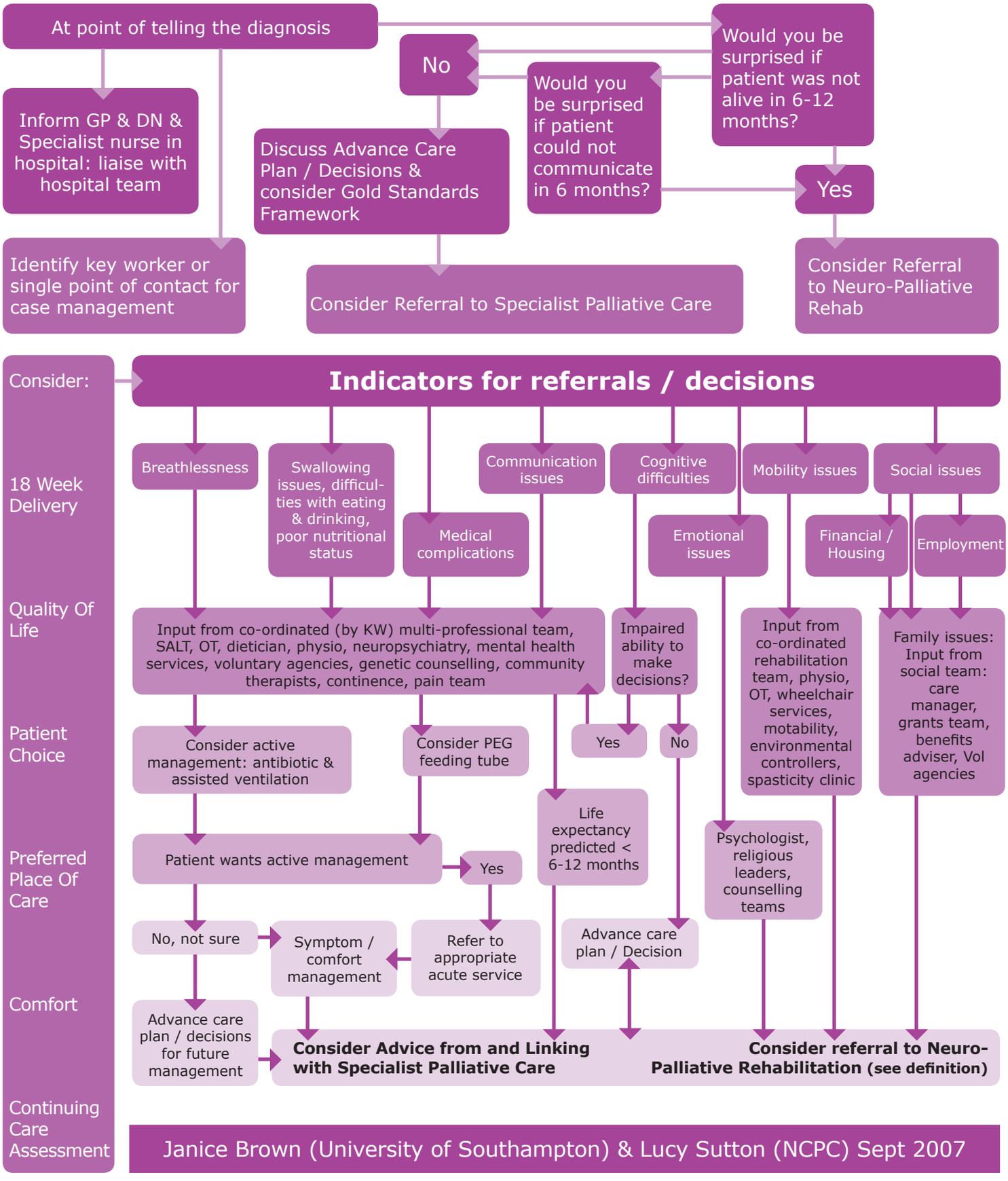
At point of telling the diagnosis
Inform GP & DN & Specialist nurse in hospital: liaise with hospital team
Identify key worker or single point of contact for case management
Would you be surprised if patient was not alive in 6-12 months?
No
Would you be surprised if patient could not communicate in 6 months?
Yes
Discuss Advance Care Plan / Decisions & consider Gold Standards Framework
Consider Referral to Specialist Palliative Care
Consider Referral to Neuro-Palliative Rehab
Consider:
Indicators for referrals / decisions
18 Week Delivery
Breathlessness
Swallowing issues, difficul-ties with eating & drinking, poor nutritional status
Medical complications
Communication issues
Cognitive difficulties
Emotional issues
Mobility issues
Social issues
Financial / Housing
Employment
Quality Of Life
Input from co-ordinated (by KW) multi-professional team, SALT, OT, dietician, physio, neuropsychiatry, mental health services, voluntary agencies, genetic counselling, community therapists, continence, pain team
Impaired ability to make decisions?
Input from co-ordinated rehabilitation team, physio, OT, wheelchair services, motability, environmental controllers, spasticity clinic
Family issues: Input from social team: care manager, grants team, benefits adviser, Vol agencies
Patient Choice
Consider active management: antibiotic & assisted ventilation
Consider PEG feeding tube
Yes
No
Life expectancy predicted < 6-12 months
Psychologist, religious leaders, counselling teams
Preferred Place Of Care
Patient wants active management
Yes
No, not sure
Symptom / comfort management
Refer to appropriate acute service
Advance care plan / Decision
Comfort
Advance care plan / decisions for future management
Consider Advice from and Linking with Specialist Palliative Care
Consider referral to Neuro-Palliative Rehabilitation (see definition)
Continuing Care Assessment
Janice Brown (University of Southampton) & Lucy Sutton (NCPC) Sept 2007