

# An integrated care pathway for life limiting neurological illness

Developed through the  
National Council for Palliative Care

Janice Brown<sup>1</sup> & Lucy Sutton<sup>2</sup>

<sup>1</sup> University of Southampton

<sup>2</sup> National Council for Palliative Care

Allied Professionals' Forum  
International Symposium on ALS/MND  
Toronto 30 November 2007  
J.B.Brown@soton.ac.uk

# The National Council for Palliative Care

- **Mission:** To promote the provision of palliative care in health and social care settings for all who need it
- **Sphere of influence:** Government policies across England, Wales and Northern Ireland
- **Four policy groups:** older persons; cancer; circulatory and respiratory conditions; neurological conditions

# Aims: Neurological Care Pathway

1. National template, with in-built triggers, for considering palliative care for people with neurological conditions
2. For use by health and social care professionals
3. 'Ideal' approach & strengthen 'key worker' concept
4. Involve all component parts of the patient's journey (pre-diagnosis to palliative care)
5. Support interface between pivotal services e.g. neurology, specialist palliative care, rehabilitation (neuro-palliative rehabilitation), voluntary agencies, social care

# What is meant by a care pathway?

- A means of improving the delivery of care to patients and families
- A way of enhancing appropriate referrals - ensuring people see the right professional at the right time
- A way of both planning and monitoring the care of a patient
- A way of encouraging seamless transitions between one service and another

# Development of Pathway

- Review of pathways in same patient groups (MND, MS, Parkinson's Disease, Huntington's Chorea)
- Review of clinical services/practices
- Review of relevant evidence (policy, research etc)
- Consultation: NCPC policy multidisciplinary group; two public consultations: web based consultations
- Versions 1 and 2 ([www.ncpc.org.uk](http://www.ncpc.org.uk))

# Initial Structure of Pathway

PATHWAY 1      Pathway to Neurological Diagnosis

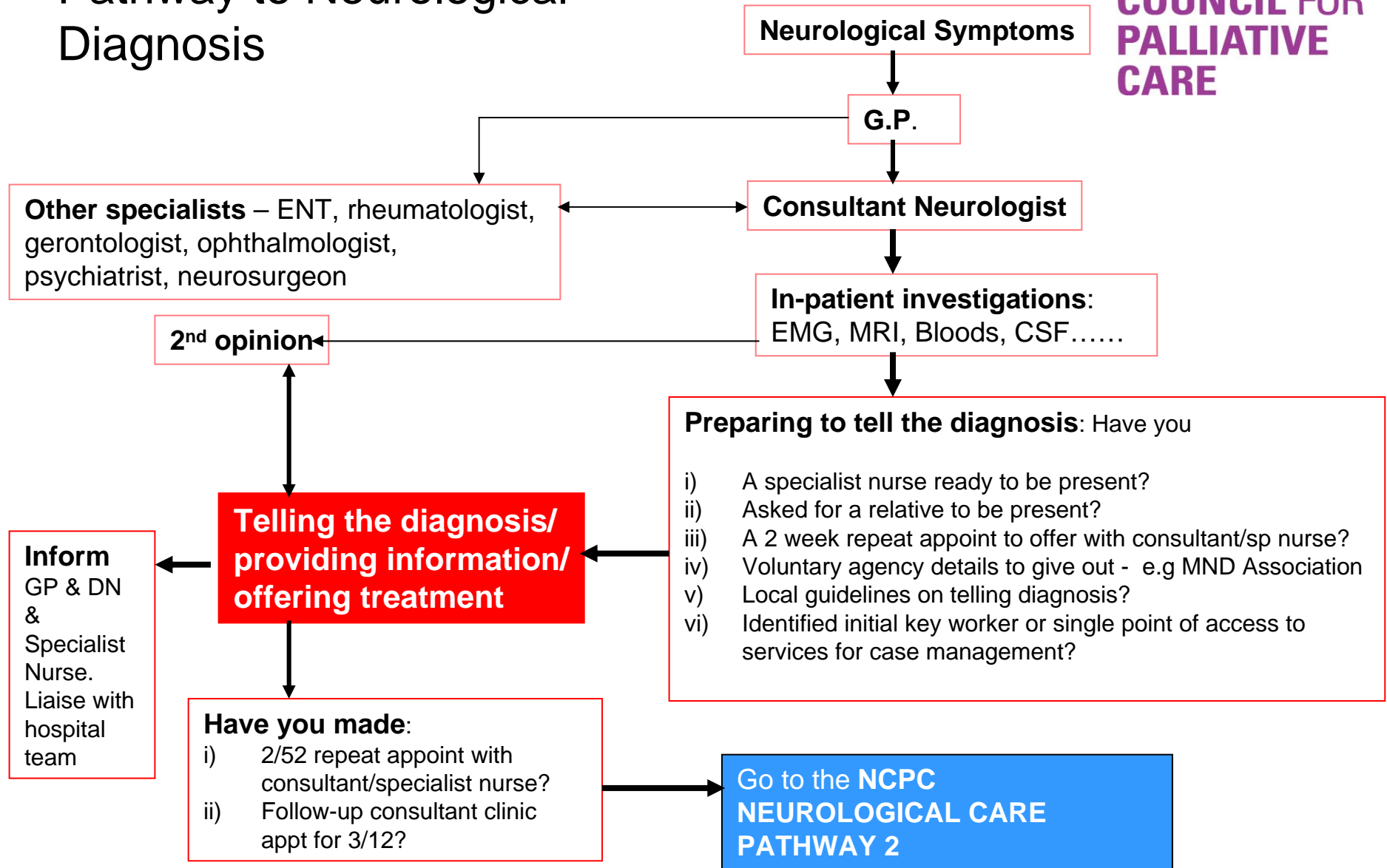
PATHWAY 2      (four parts)

- 2i)    At diagnosis and early action considerations
- 2ii)    Slow deteriorating neurological conditions
- 2iii)    Fast deteriorating neurological conditions
- 2iv)    Variable deteriorating neurological conditions

# Pathway 1

## Pathway to Neurological Diagnosis

THE  
NATIONAL  
COUNCIL FOR  
PALLIATIVE  
CARE



# Considerations

- In these pathways we are talking about ideals, recognising that services may be limited in what can be offered
- **Neurological conditions vary in presentation but often there are parallels with symptoms and need for services**
- **It is very difficult to make some diagnoses: require a time period for further observation: require a second opinion**

# Revised Structure of Pathway Two

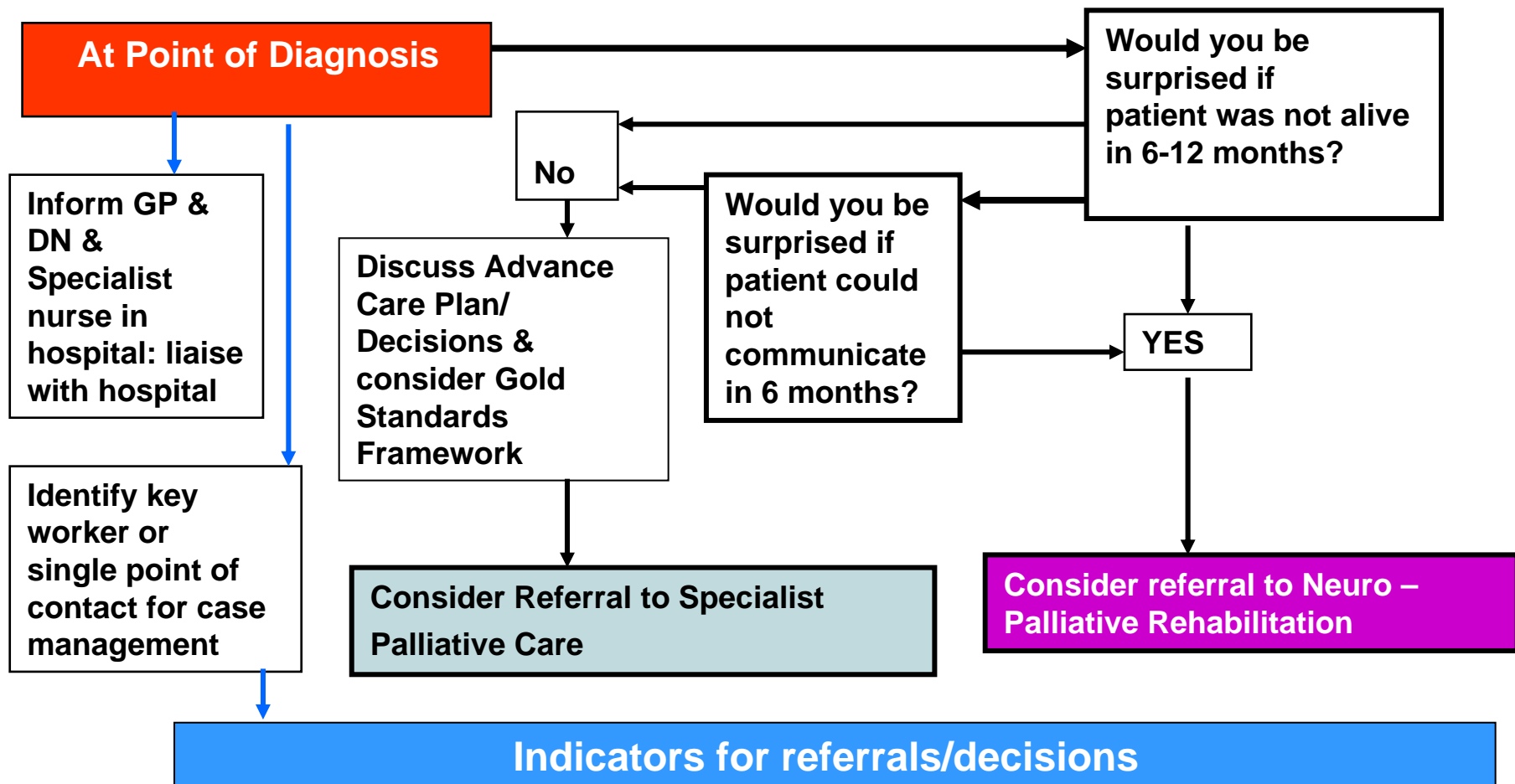
**Part 1**      At Diagnosis and Early Action Considerations

**Part 2**      Neurological Care Pathway

- \*Indicators for Referral
- \*\*Attention to Policy
- \*\*\*Full neurological care pathway

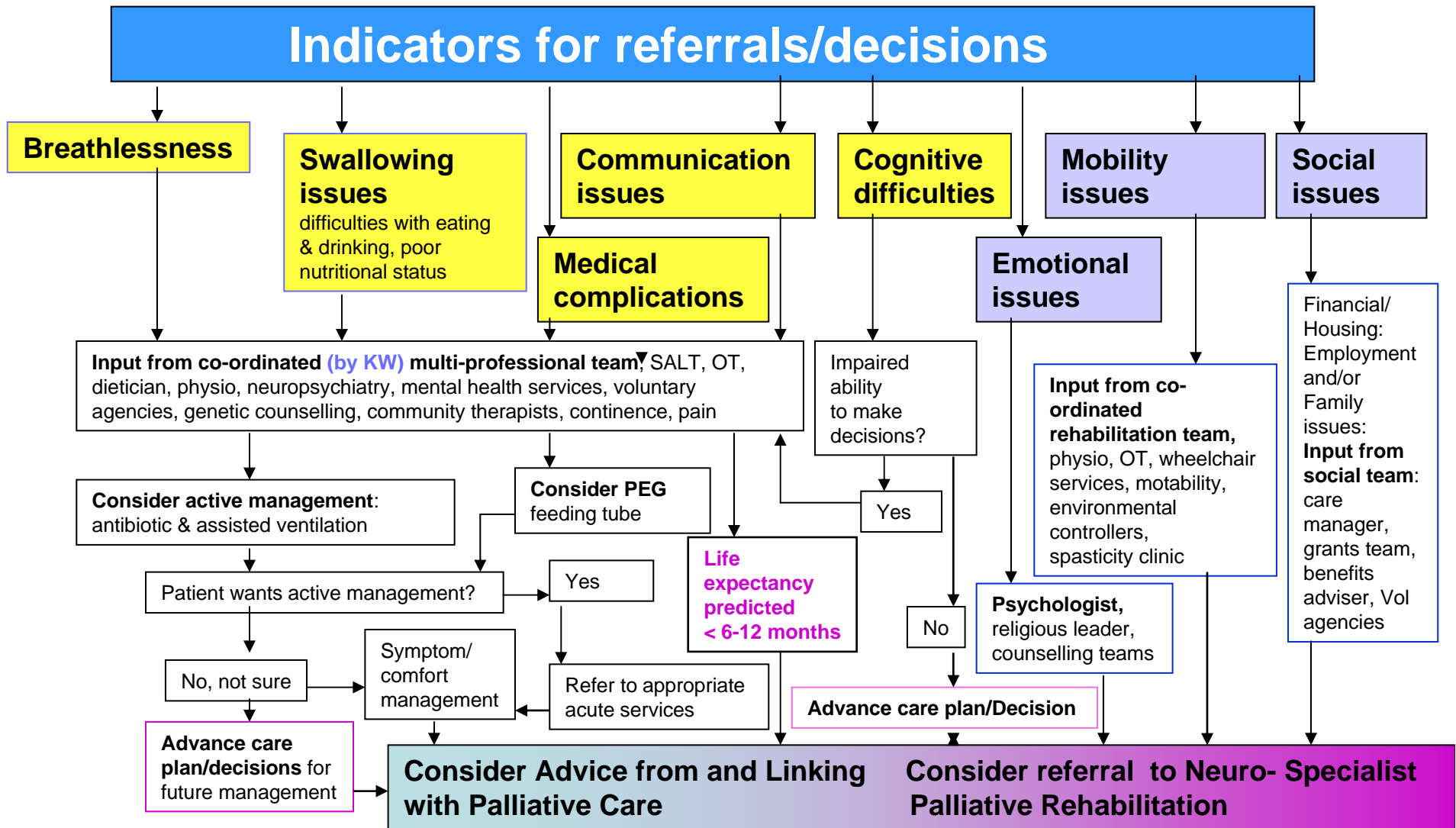
# Pathway 2

## Part 1: At Diagnosis and Early Action Considerations



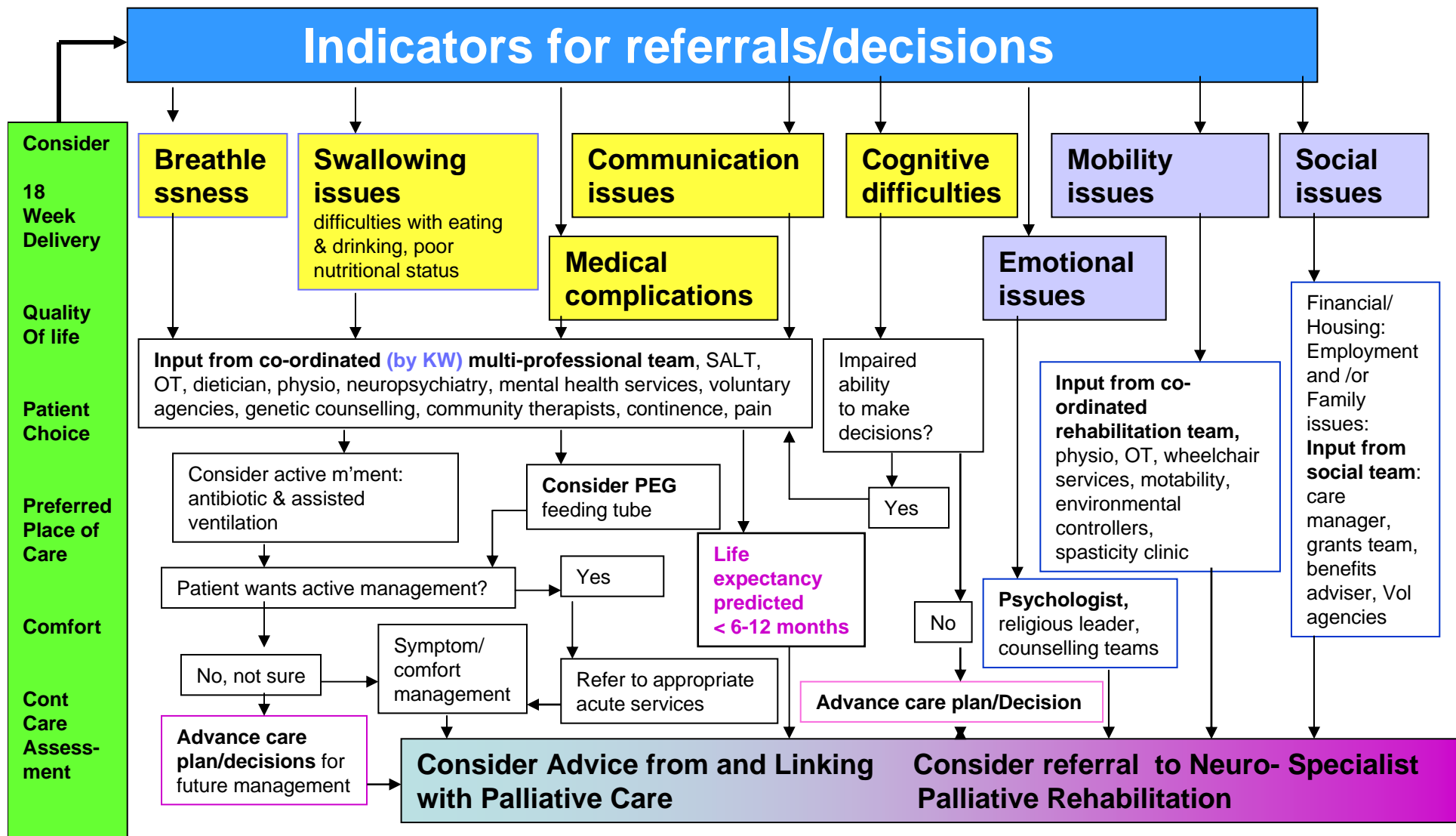
# Pathway 2

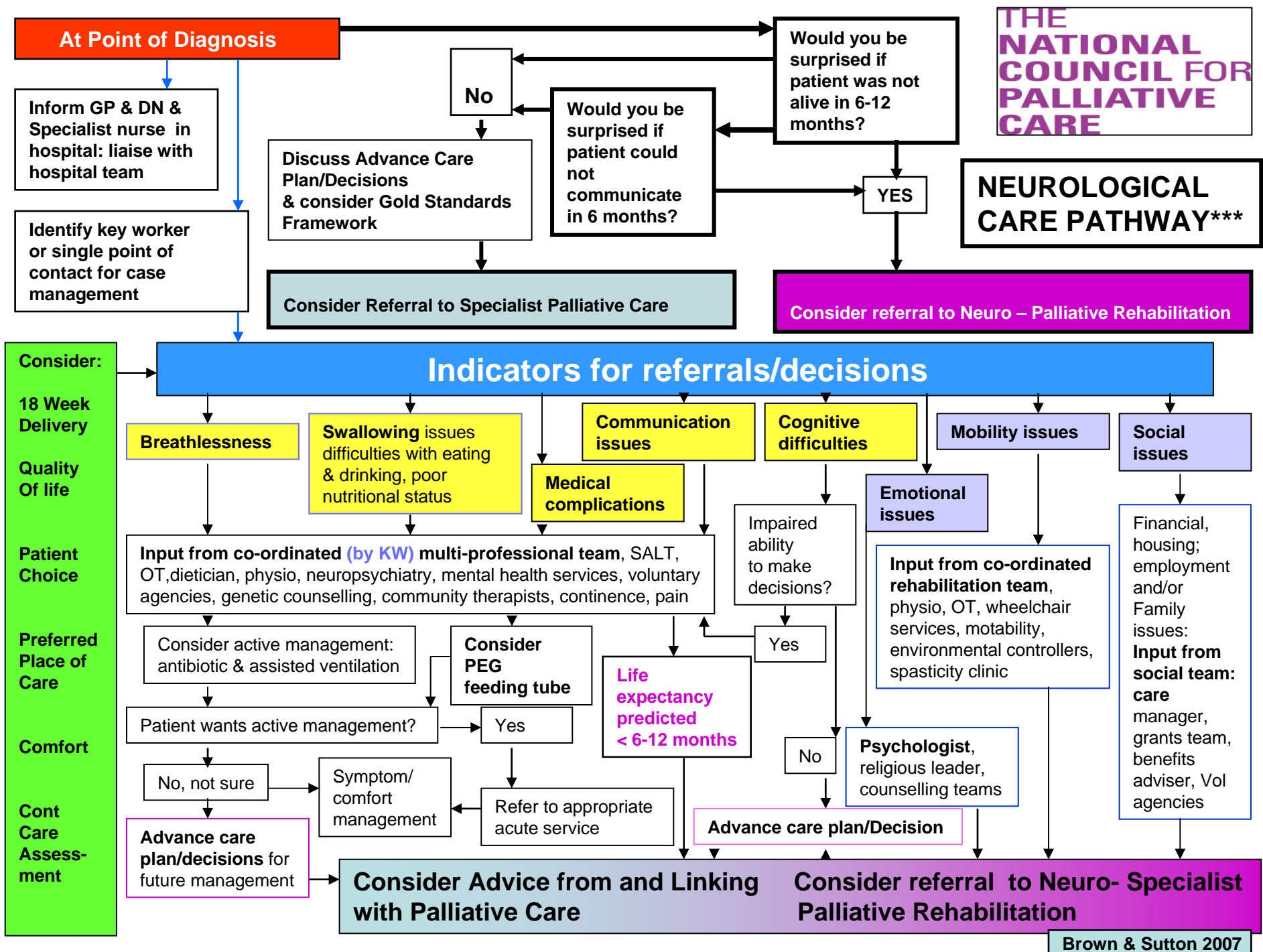
## Part 2\* Indicators for referral



# Pathway 2

## Part 2\*\* Indicators for referral & attention to policy





# Conclusions

- A national, accessible template for neurological conditions  
(Focus on Neurology [www.ncpc.org.uk](http://www.ncpc.org.uk))
- Guidance for service delivery:
  - i) support people with neurological conditions
  - ii) in-built triggers for appropriate referrals
  - iii) extends from diagnosis to end of life care
  - iv) promote communication & interaction between pivotal services – neurology, rehabilitation and specialist palliative care
  - v) promotes key worker role
- Supporting mission of NCPC

# An integrated care pathway for life limiting neurological illness

## Acknowledgments

NCPC Neurological Conditions Policy Group  
UK MND Professional Network  
Consultation participants

Allied Professionals' Forum  
International Symposium on ALS/MND  
Toronto 30 November 2007  
J.B.Brown@soton.ac.uk