**PHASE MODEL / LIFE TRAJECTORY (in relation to supportive and palliative care)**

***Antenatal awareness***

*Genetic testing*

*Foetal assessment*

***Birth***

*Gradual accrual of disease burden*

*Impact on well-being at a level that is ‘ok’*

*Condition management (aggressive)*

*Symptomatic relief*

**Diagnosis**

Disease burden reaches critical mass

or

Something ‘big’ happens

**Early / ‘Aggressive Disease Management’ (ADM)**

Good/adequate response to treatment

Symptomatic relief

Wellbeing maintained/diminishing but at acceptable level

Varying awareness of ‘enormity’ of it all

**Complex**

Continuing ADM but with less response / impact

Symptomatic relief

Diminishing wellbeing (speed critical)

Increasing awareness of ‘enormity’ of it all

Acceptance level

**Prodromal**

Continuing or diminishing ADM

Symptomatic relief

Diminishing wellbeing (speed critical)

Increasing acceptance of ‘enormity’ of it all

**Last Stages of Life**

Cessation of ADM

Symptomatic relief

Rapidly diminishing wellbeing

Acceptance (?) of enormity of it all and of impending death

**Death**

**Legacy**

Impact of individual’s life/death on those left behind

**Key issues (some)**

Disease burden level

 How much can the individual ‘stand’? –

How individual/variable is it?

Disability threshold

 Who sets this?

 How individual is it?

Independency / dependency threshold

Treatment aims

Disease modification (and response)

Supportive (not a good term!) / Symptom relief

Level of agreement (amongst all concerned)

Awareness of seriousness level

 How much does the patient want to know?

 How much does health care wish to tell?

 What are the underlying health beliefs of the patient?

Acceptance of seriousness level

 Coping strategies

Level of certainty/uncertainty

 Health care

 Patient / carers

The Index of Concern

 A complex interplay of level of seriousness and level of uncertainty

 As seriousness or uncertainty increase then so does the index of concern

If both seriousness and uncertainty increase then the index of concern rises more steeply