

- Confused by medicalized language
- Lacking personal relevance
- Baffled by imprecision in meaning
- Opposed to obsolete terms

Frustrated by
ambiguity

- Confronting reality
- Enabling planning and preparation
- Taking ownership for change
- Learning medical terms for self-advocacy
- Educating others

Mobilizing
self-
management

Provoking and
exacerbating
undue trauma

- Fear of the unknown
- Denoting impending death
- Despair in having incurable and untreatable disease
- Premature labeling and assumptions
- Judgment, stigma and failure of self

Making sense of
the prognostic
enigma

- Conceptualizing level of kidney function
- Correlating with symptoms and life impact
- Predicting progression and need for intervention