

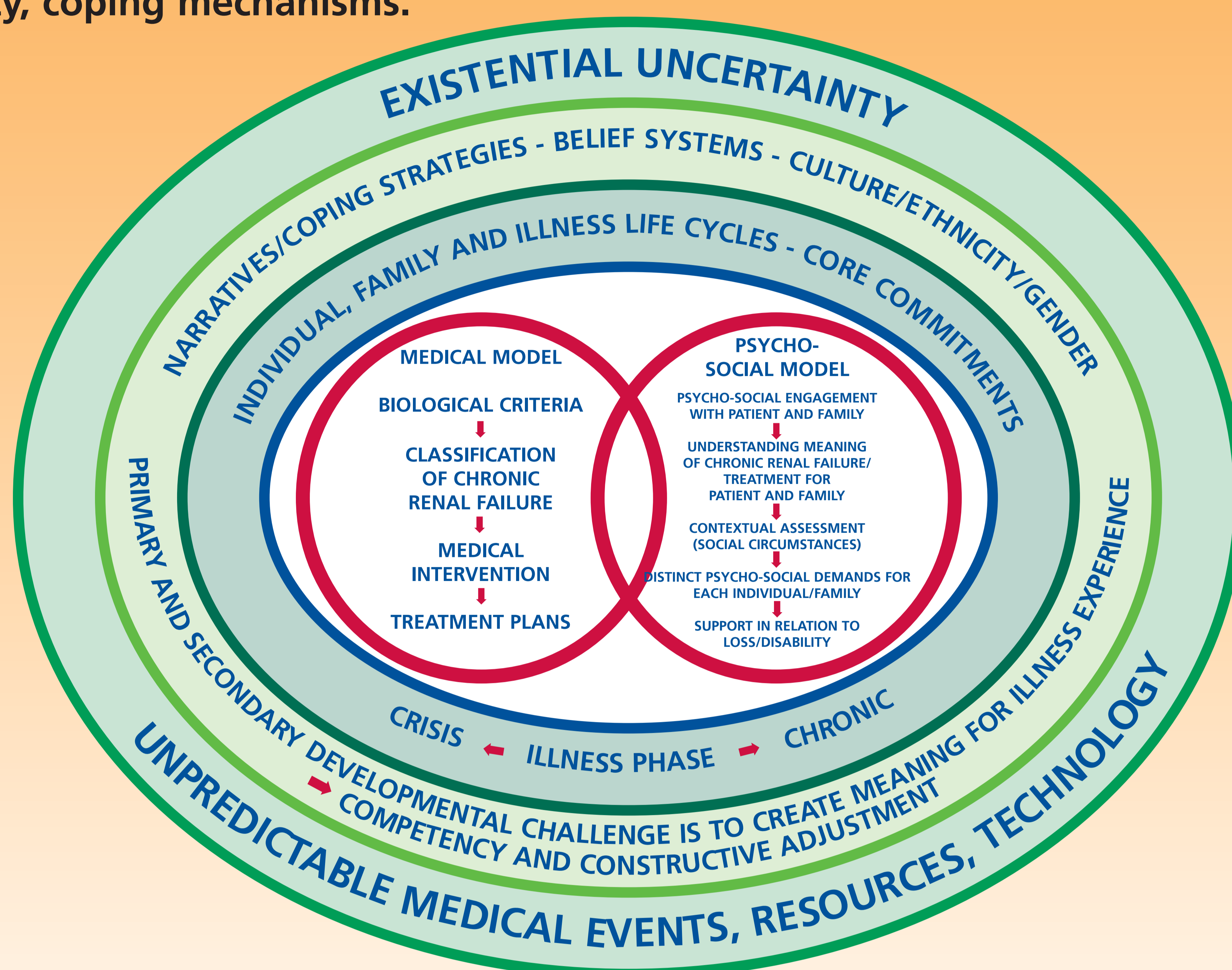
# ILLNESS - A Family Affair

## A Systemic Approach to Understanding and Care For Patients With Chronic Renal Failure

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Psycho-social demands for the patient, family and staff can be related to each stage of the illness and to different components of family functioning - communication, problem-solving, role flexibility, coping mechanisms.



### Illness Patterning in Relation to Cumulative Individual/Family and Professional Challenges

#### DIAGNOSIS/AETIOLOGY

Symptomatic/Asymptomatic periods prior to, and following, diagnosis of chronic renal failure/treatment plan

Onset - sudden/gradual/premature

Other associated medical conditions - Hypertension/Diabetes

Hereditary - Polycystic Kidney disease

#### PRIMARY CHALLENGES

Grieving loss of pre-illness individual and family identity

Coping with sense of responsibility/guilt in relation to other family members/acknowledging reality of renal failure

Accepting long term/life-threatening nature of condition whilst maintaining sense of control for all family members

Adjusting to illness-related symptoms and associated treatment

Family re-organisation/role flexibility

Engaging with professionals in health setting/significance of professional approach in 'framing the event'

#### COURSE

Progressive - End-stage renal failure/bone disease/associated medical events ( CVA/MI)

Constant - Routine Dialysis

Episodic/relapsing - access complications/infections/unstable BP

#### SECONDARY CHALLENGES

Pacing

Sustaining autonomy for all family members

Maintaining balanced mutual relationships with the dynamics of patient/caretaker

Redefining individual/family goals

Sustaining intimacy in the face of threatened loss

Continuing role change

Coping with financial/life-style adjustments

Coping with the psychological discrepancy between routine demands and crises

#### OUTCOME

##### PHYSICAL IMPACT/DISABILITY

- loss of stamina (anaemia), impaired mobility (peripheral vascular disease)
- disfigurement (P.D. catheter/fistula)
- impairment of sensation/cognition (MI)
- loss of libido/fertility

Extent, type and timing will affect degree of stress.

Challenges expectations of self and others within intimate relationships.

Productive responses in accomodating disability or unproductive coping mechanisms e.g. misdirected anger, self-destructive denial and over-adaptation to the role of patient.

Importance of care staff in clarifying capability.

##### PLANNED AND UNANTICIPATED MEDICAL TREATMENTS/EVENTS INVOLVING HOPE/LOSS

Transplantation/Home Dialysis/Unit Haemodialysis/Deciding to stop Dialysis or deciding not to dialyse/Peritonitis or other complications resulting in change of treatment option.

Anxiety and Depression/Grief related to set-backs/hope related to positive changes in treatment outcome. Challenges initial expectations of patient family/staff members.

##### CONSERVATIVE MANAGEMENT/ TERMINAL CARE

Letting go

Emotional openness and lot of practical tasks

Separation/mourning

Re-organisation around loss

Care management

The Developmental Nature of Chronic Renal Failure and Associated Psycho-Social Challenges Demands a Holistic Approach With Specialist Psycho-Social Support Staff For Each Renal Unit.