

## NEED FOR REGULAR ASSESSMENT



### BACKGROUND

**High symptom burden can interfere with physical functioning and diminish life satisfaction, and may result in more hospitalizations and higher mortality**

The Dialysis Symptom Index measures as many as 30 key patient-identified symptoms (Figure 1), with most patients reporting a median of 9 symptoms

There is high discordance between symptoms experienced by people on dialysis and those prioritized for treatment by their care providers. For example, in one report, only half of hemodialysis patients with bone pain received analgesia



### CARE GAPS

The focus of care for dialysis patients primarily has been to meet numerical laboratory targets

Routine symptom assessment is not universal or standardized in dialysis care

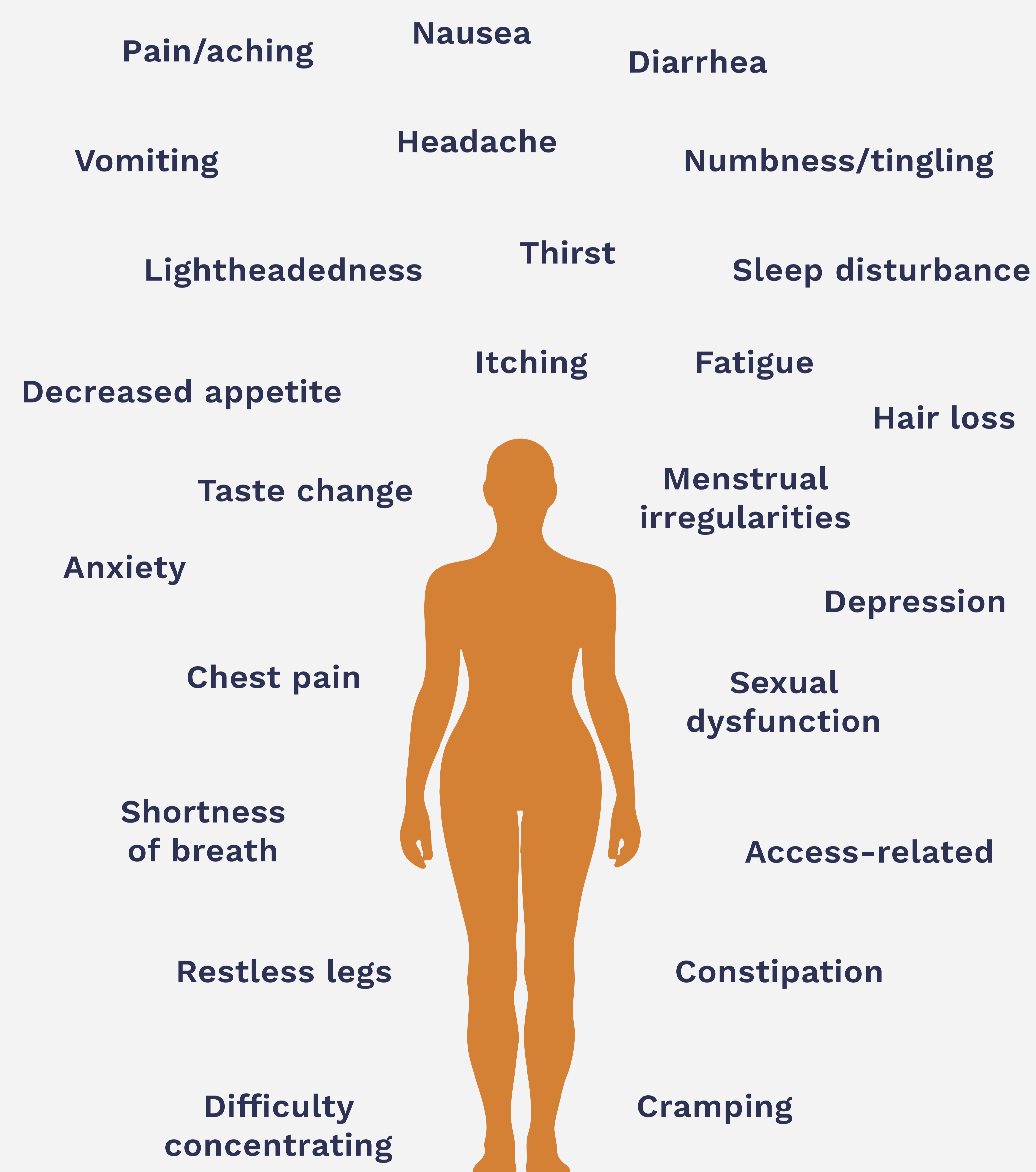
Clinicians often do not ask people on dialysis about their well-being, symptoms, or daily functioning

Patients may have difficulty revealing and describing symptoms they consider to be taboo, such as pain, sexual symptoms, itch, or depressive symptoms



### SYMPTOMS IN DIALYSIS PATIENTS

**Symptoms that kidney care teams should address**



**Patient-identified symptoms**



### RATIONALE FOR ROUTINE SYMPTOM ASSESSMENT

Early recognition and intervention can:

- ★ mitigate negative effects of symptoms and reduce their overall burden,
- ★ improve physical functioning,
- ★ and enhance health-related quality of life

Even when treatment options are limited, acknowledging and discussing symptoms is important; feeling heard and understood matters to patients and can also be therapeutic



### APPROACHES FOR ASSESSMENT

Regular symptom screening should be incorporated into clinical practice and should involve a dialogue between the patient and the clinician, with a focus on symptoms that are most important or bothersome to the patient.

Dialysis care team can ask open-ended questions, such as:

- ★ How are you feeling?
- ★ Is there anything interfering with your life goals?
- ★ Has anything changed?
- ★ What is bothering you most?

Providing patients with a list of symptoms can serve to normalize and elicit reporting

Identifying clusters of symptoms that tend to coexist can help clinicians to inquire about other possible symptoms and support symptom prevention

Symptom assessment should be fully documented in the medical chart and be made accessible to all multidisciplinary care team members

Follow-up should be done routinely, such as every 1-3 months



## MANAGEMENT OF SYMPTOMS



### SYMPTOMS

**Symptoms can arise from dialysis treatment-related factors or other coexisting chronic medical conditions**

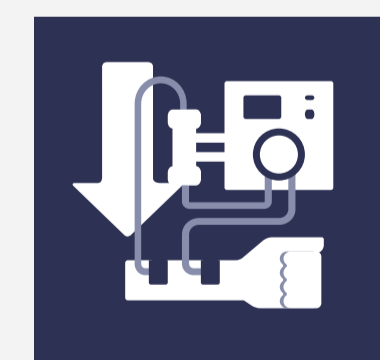
Symptoms are not isolated and often cluster

Symptoms can have cascading effects. For example, major depressive disorder can lead to changes in sleep, and insomnia can lead to increased pain perception or anxiety

Symptoms can be managed with:

- ★ changes in the dialysis prescription,
- ★ nonpharmacologic strategies,
- ★ medications,
- ★ or a combination of these

Choice of management should be based on shared decision-making and should be individualized



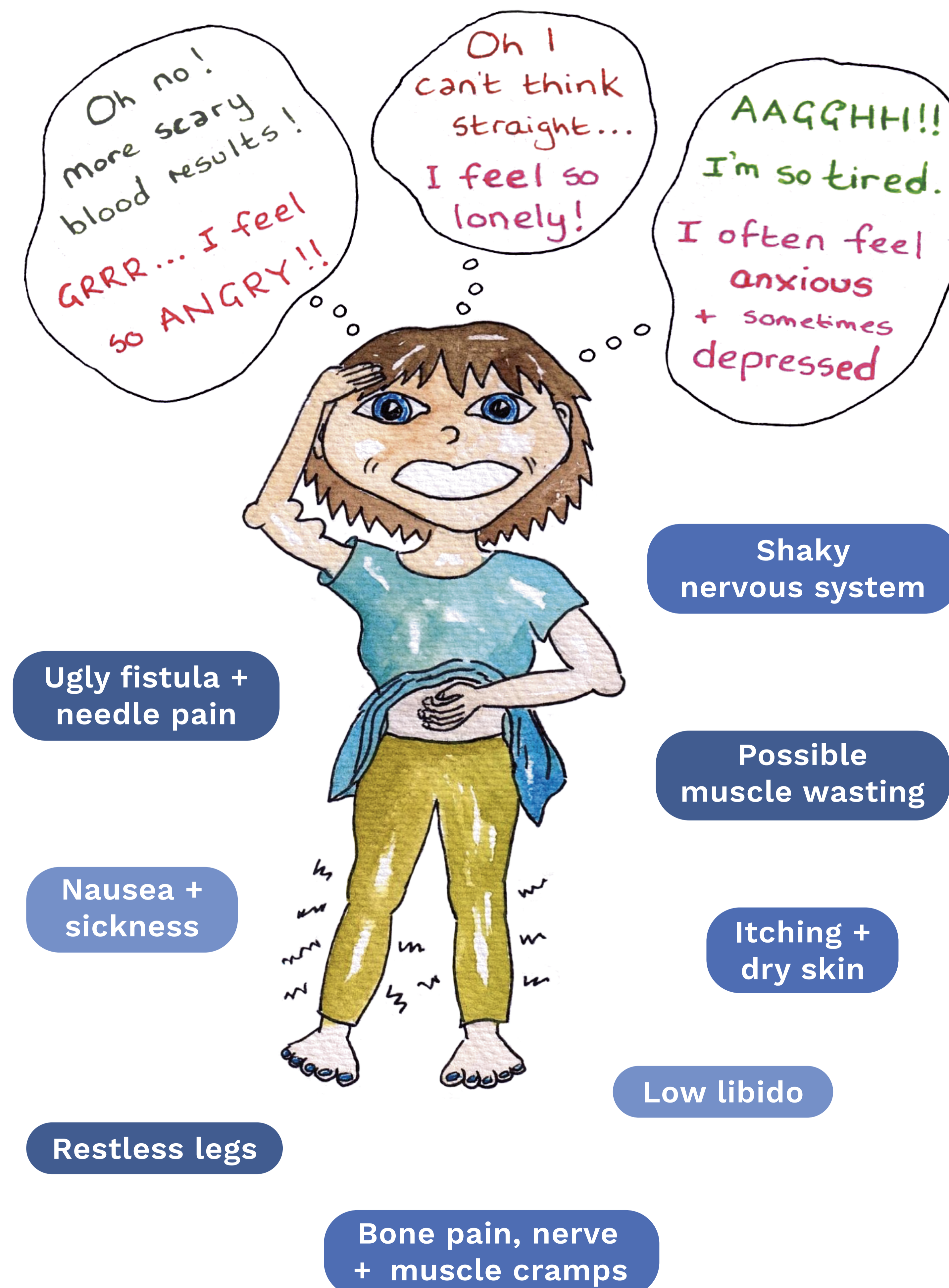
### DIALYSIS PRESCRIPTION

Mode of dialysis delivery (hemodialysis, peritoneal dialysis, extended hemodialysis) has a significant clinical impact on physical or psychological symptom burden

Tailoring the dialysis prescription to align with individual patient goals is important



### SYMPTOM PERSPECTIVES FROM PATIENTS ON DIALYSIS



### NONPHARMACOLOGICAL APPROACHES

Nonpharmacologic interventions include:

- ★ cognitive behavioral therapy or other forms of psychotherapy,
- ★ social or peer support,
- ★ exercise,
- ★ addressing socioeconomic factors, such as income, employment, food and housing insecurity,
- ★ mindfulness,
- ★ and meditation

Benefits include flexibility in delivery mode and accessibility (e.g., during intradialytic intervals), and a lower burden of polypharmacy



### PHARMACOLOGICAL APPROACHES

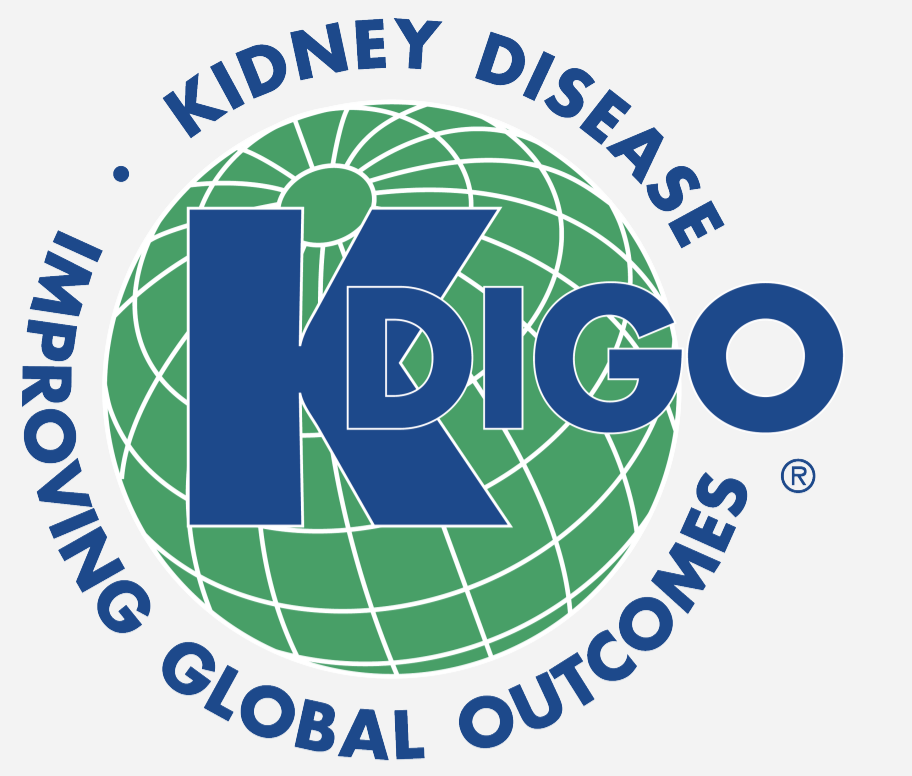
Choice of management should be based on shared decision-making and should be individualized

Consider use of medications that may have efficacy across several symptoms which may help mitigate polypharmacy

Most pharmacological treatments have not been formally evaluated in the dialysis population. However, emerging therapy such as the highly selective kappa opioid receptor agonist difelikefalin is now available to address pruritus specifically in patients undergoing hemodialysis



# Management of Symptom Burden in Dialysis Patients



## MULTIDISCIPLINARY ENGAGEMENT FOR MANAGING DIALYSIS SYMPTOMS AND PROMS



### MULTIDISCIPLINARY ENGAGEMENT

Expertise from nurses and other members on the multidisciplinary care team (right figure) are valuable for initiating comprehensive physical, psychological, and social assessments

Team members can attend to the feelings and concerns related to symptom experiences and document them for sharing with other kidney health professionals

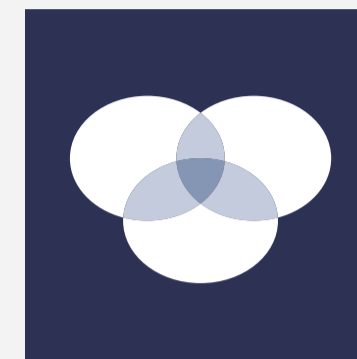
Diverse care team members can help bridge any gaps in perspectives that may arise, for example, from culture, religion, age, or sex or gender



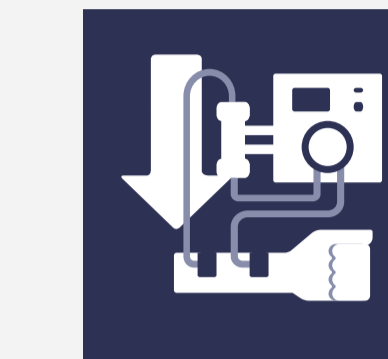
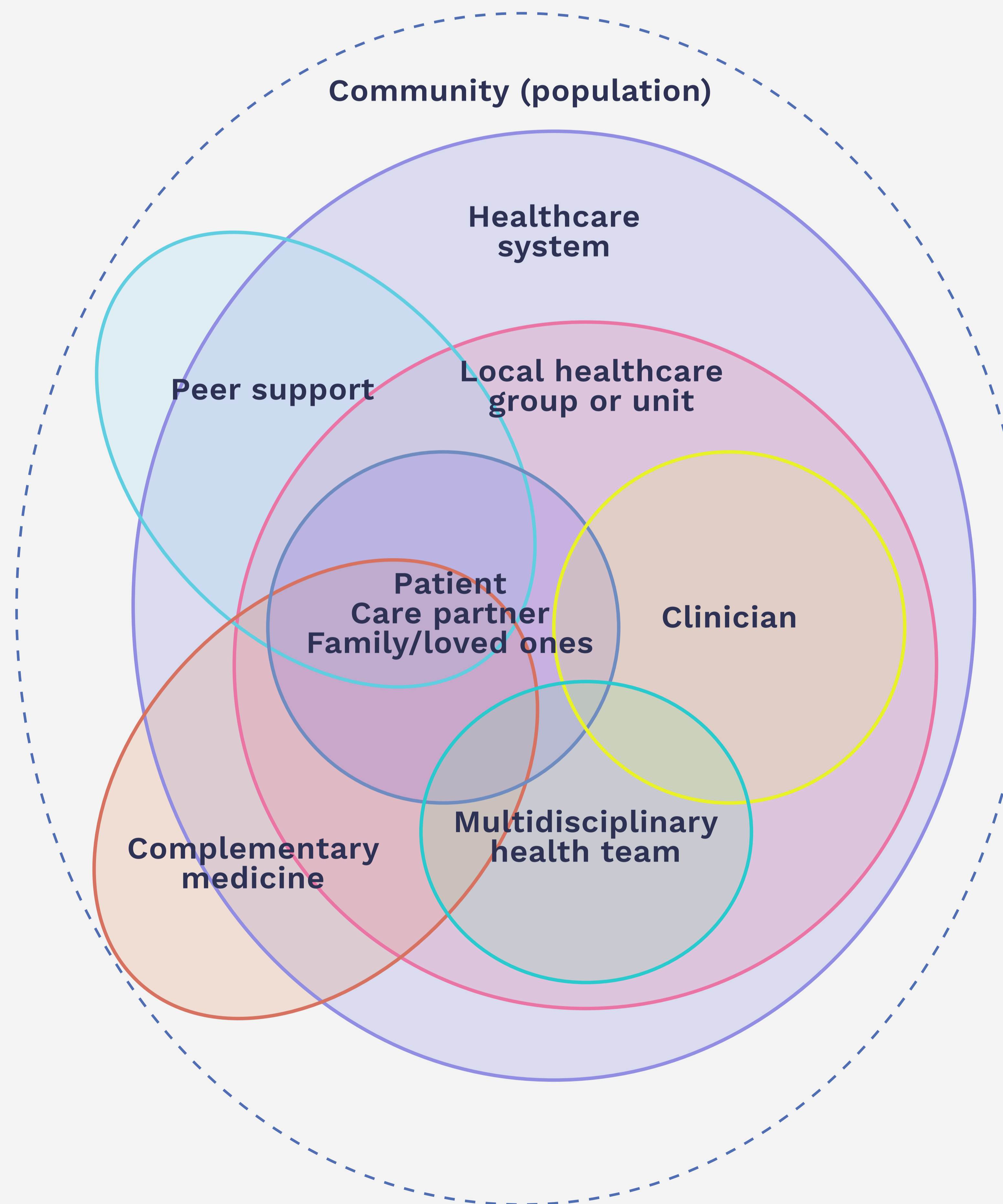
### ROLE OF PROMS

Symptom assessment may be guided with the use of an appropriate patient-reported outcome measure (PROM)

PROMs may help not only to identify symptoms but enhance the patient-provider relationship, improve communication, and support shared decision-making



### CARE TEAM COMPONENTS



### AVAILABLE PROMS FOR COMPREHENSIVE SYMPTOM ASSESSMENT IN DIALYSIS PATIENTS

- ★ Edmonton Symptom Assessment System: revised—Renal (ESAS-r:R)
- ★ Integrated Palliative Care Outcome Scale—Renal (iPOS-renal; <https://pos-pal.org/maix/ipos-renal-in-english.php>)
- Dialysis Symptom Index
- ★ Choices for Healthy Outcomes in Caring for ESRD (CHOICE) Health Experience Questionnaire
- Symptom Monitoring on Renal Replacement Therapy-Hemodialysis (SMaRRT-HD)



## CONSENSUS POINTS REGARDING IDENTIFYING AND MANAGING DIALYSIS-RELATED SYMPTOMS

1. Dialysis care team should assess and focus on symptoms most important to individual patients and develop a care plan to address them
2. Prioritization in symptom management should be based on patient perceptions of which symptoms are most negatively impacting their ability to live the life they want. Care providers often fail to recognize the impact symptoms can have on functioning
3. Nephrology multidisciplinary teams should take the lead in symptom management, with holistic care as the goal. Nephrology nurses can perform routine symptom assessment and initiate multidisciplinary action by engaging other team members (e.g., nephrologists, psychologists, social workers) to manage distressful symptoms. Comprehensive physical, psychological, and social assessments can be performed to identify and prioritize symptoms and needs of patients for management
4. The approach to routine symptom screening should remain consistent regardless of dialysis modality
5. Regular global symptom screening should be incorporated into routine clinical practice. This should ideally involve using: i) an open-question approach that explores patient priorities for symptom management AND ii) standardized PROMs
6. PROMs play an important role in identifying patient-prioritized symptoms but should not be used in isolation.
7. PROMs for guiding clinical care should be:
  - ★ Relevant to patients with kidney diseases, with evidence for validity
  - ★ Short and simple, requiring limited burden/resources for completion
  - ★ Adaptable for language and vulnerable patients, e.g., those who are frail or have cognitive impairment and/or low health literacy
  - ★ Reliable and sensitive to change if being used to monitor treatment
8. The frequency of routine symptom screening should be individualized
9. Symptom assessments should be incorporated into patient medical records to facilitate integration into overall clinical assessment AND should be accessible to the interdisciplinary team within and beyond nephrology and the patient
10. Healthcare use and cost effectiveness studies for symptom assessment and management programs are needed