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CLINICAL PRACTICE GUIDELINES

CONSERVATIVE KIDNEY MANAGEMENT FOR ADVANCED CHRONIC KIDNEY DISEASE



**MINISTRY OF HEALTH
MALAYSIA**



**ACADEMY OF MEDICINE
MALAYSIA**



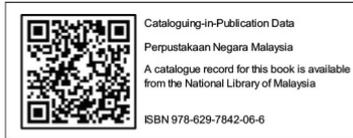
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STATEMENT OF INTENT

This clinical practice guideline (CPG) is meant to be a guide for clinical practice, based on the best available evidence at the time of development. The guideline should not override the responsibility of the practitioners to make decisions appropriate to the circumstances of the individual. This should be done in consultation with the patients and their families or guardians, taking into account the management options available locally.

UPDATING THE CPG

These guidelines were issued in 2025 and will be reviewed in a minimum period of four years (2029) or sooner if new evidence becomes available. When it is due for updating, the Chairperson of the CPG or National Advisor of the related specialty will be informed about it. A discussion will be done on the need for a revision including the scope of the revised CPG. A multidisciplinary team will be formed, and the latest systematic review methodology used by MaHTAS will be employed. Every care is taken to ensure that this publication is correct in every detail at the time of publication. However, in the event of errors or omissions, corrections will be published in the web version of this document, which will be the definitive version at all time. This version can be found on the websites mentioned above.

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LEVELS OF EVIDENCE

Level	Study design
I	Properly powered and conducted randomised controlled trial; well-conducted systematic review or meta-analysis of homogeneous randomised controlled trials
II-1	Well-designed controlled trial without randomisation
II-2	Well-designed cohort or case-control analysis study
II-3	Multiple time series, with or without the intervention; results from uncontrolled studies that yield results of large magnitude
III	Opinions of respected authorities, based on clinical experience; descriptive studies or case reports; reports of expert committees

SOURCE: U.S. Preventive Services Task Force. U.S. Preventive Services Task Force Procedure Manual. Rockville, MD: USPSTF; 2015.

FORMULATION OF RECOMMENDATION

- In line with the new development in CPG methodology, the CPG Unit of MaHTAS is adapting **Grading Recommendations, Assessment, Development and Evaluation (GRADE)** in its work process. The quality of body of evidence and related effect size are carefully assessed/reviewed by the CPG Development Group (DG).
- Recommendations are formulated based on **certainty of evidence** and the wording used denotes the **strength of recommendations**. This takes into account:
 - quality and level of the evidence
 - balance of benefits and harms of the options
 - patient's preference and values
 - resource implications
 - relevancy and applicability to the local target population
- The more criteria being fulfilled, the more certain is the evidence leading to strong recommendations using the word "**should**" being considered. Otherwise, weak recommendations use the word "**may**" in proposing an action to be made.
- In the CPG, a yellow box highlights important message(s) in the management while a blue box contains evidence-based recommendation(s) for the particular condition.

KEY RECOMMENDATIONS

The following recommendations are highlighted by the CPG DG as the key recommendations that answer the main questions addressed in the CPG and should be prioritised for implementation.

- Patients, caregivers and healthcare providers should be educated on conservative kidney management (CKM) options for advanced chronic kidney disease (CKD).
- Shared decision-making and advance care planning should be incorporated in the management for all persons with advanced CKD.
- The management of symptoms in persons with advanced CKD receiving CKM should be tailored to the person, with a focus on identifying and addressing any underlying causes using non-pharmacological and pharmacological approaches.
- For stable persons with advanced CKD receiving CKM, the following should be considered:
 - protein intake of 0.6 - 0.8 g/kg body weight/day
 - sodium intake <2 g/day

GUIDELINES DEVELOPMENT AND OBJECTIVES

GUIDELINES DEVELOPMENT

The members of the Development Group (DG) for these Clinical Practice Guidelines (CPG) were from the Ministry of Health (MoH) and Ministry of Higher Education. There was active involvement of a multidisciplinary Review Committee (RC) during the process of the CPG development.

A systematic literature search was carried out using the following electronic databases: mainly Medline via Ovid and Cochrane Database of Systemic Reviews and others e.g. PubMed and Guidelines International Network (refer to **Appendix 1 for Example of Search Strategy**). The search was limited to literature published on humans, publication from year “1946 to Current” and English language. In addition, the reference lists of all retrieved literature and guidelines were searched, and experts in the field contacted to identify relevant studies. All searches were conducted from 15 November 2023 to 10 December 2024. Literature searches were repeated for all clinical questions at the end of the CPG development process allowing any relevant papers published before 31 January 2025 to be included. Future CPG updates will consider evidence published after this cut-off date. The details of the search strategy can be obtained upon request from the CPG Secretariat.

References were also made to other CPGs which are:

- KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease
- European Society for Clinical Nutrition and Metabolism (ESPEN) practical guideline on clinical nutrition in hospitalized patients with acute or chronic kidney disease 2024
- Kidney Disease Outcomes Quality Initiative (KDOQI) clinical practice guideline for nutrition in CKD: 2020 update

These CPGs were evaluated using the Appraisal of Guidelines for Research and Evaluation (AGREE) II prior to them being used as references. A total of four clinical questions (CQ) were developed under different sections. Members of the DG were assigned individual questions within these sections (refer to **Appendix 2 for Clinical Questions**). The DG members met 18 times throughout the development of these guidelines. All literature retrieved were appraised by at least two DG members using Critical Appraisal Skill Programme checklist, presented in evidence tables and further discussed in each DG meetings. All statements and recommendations formulated after that were agreed upon by both the DG and RC. Where evidence was insufficient, the recommendations were made by consensus of the two groups. This CPG was developed largely based on the findings of systematic reviews and clinical trials, with local practices taken into consideration.

The literature used in these guidelines were graded using the U.S. Preventive Services Task Force Level of Evidence (2015), while the grading of recommendation was done using the principles of GRADE (refer to page i). The writing of the CPG follows strictly the requirement of AGREE II.

On completion, the draft of the CPG was reviewed by external reviewers. It was also posted on the MoH Malaysia official website for feedback from any interested parties. The draft was finally presented to the Technical Advisory Committee for CPG and, the HTA and CPG Council MoH Malaysia for review and approval. Details on the CPG development methodology by MaHTAS can be obtained from Manual on Development and Implementation of Evidence-based Clinical Practice Guidelines published in 2015 (Available at https://www.moh.gov.my/moh/resources/CPG_MANUAL_MAHTAS.pdf).

OBJECTIVES

The aim of this CPG is to assist clinicians and other healthcare providers in making evidence-based decisions for persons with advanced CKD stages 4 and 5 receiving CKM. It aims to improve quality of life by making recommendations on these aspects:

- assessment and planning
- treatment
- follow-up

CLINICAL QUESTIONS

Refer to **Appendix 2**.

TARGET POPULATION

Inclusion Criteria

- Adult persons with CKD Stage 4 and 5
- Non-dialysis care

Exclusion Criteria

- Persons with CKD planning for or undergoing dialysis/transplantation

TARGET GROUP/USERS

This document is intended to guide healthcare professionals and relevant stakeholders involved in the management of persons with advanced CKD receiving CKM. This includes:

- i. healthcare providers
- ii. trainees and students
- iii. persons with advanced CKD stage 4 and 5 and their caregivers
- iv. professional societies and NGOs
- v. policy makers

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Primary, secondary and tertiary care settings

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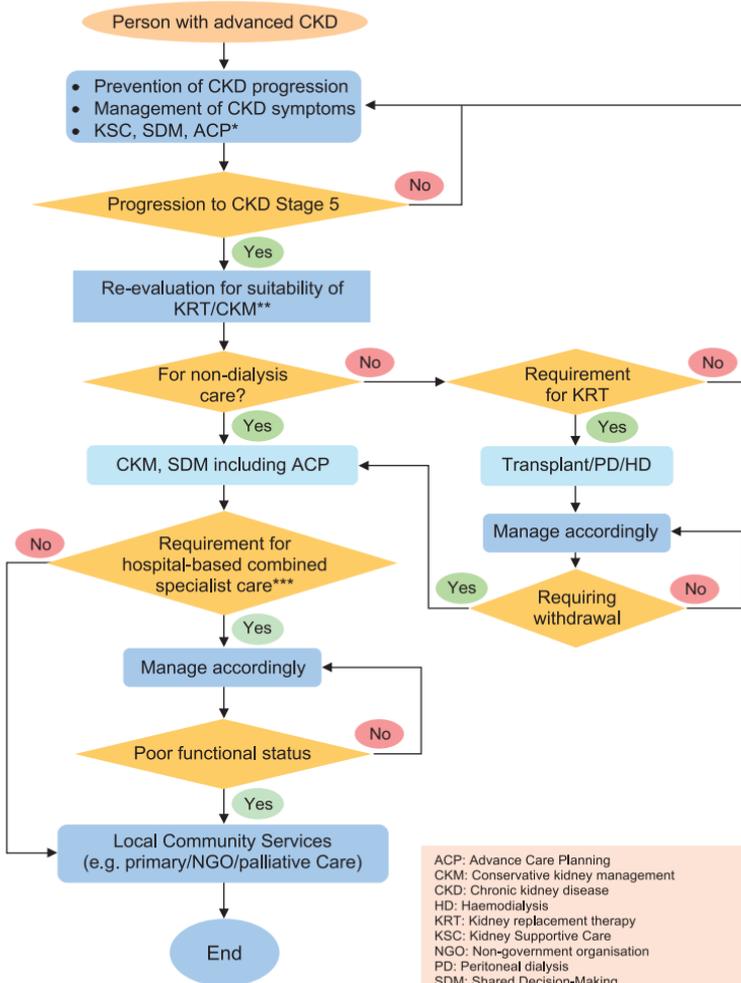
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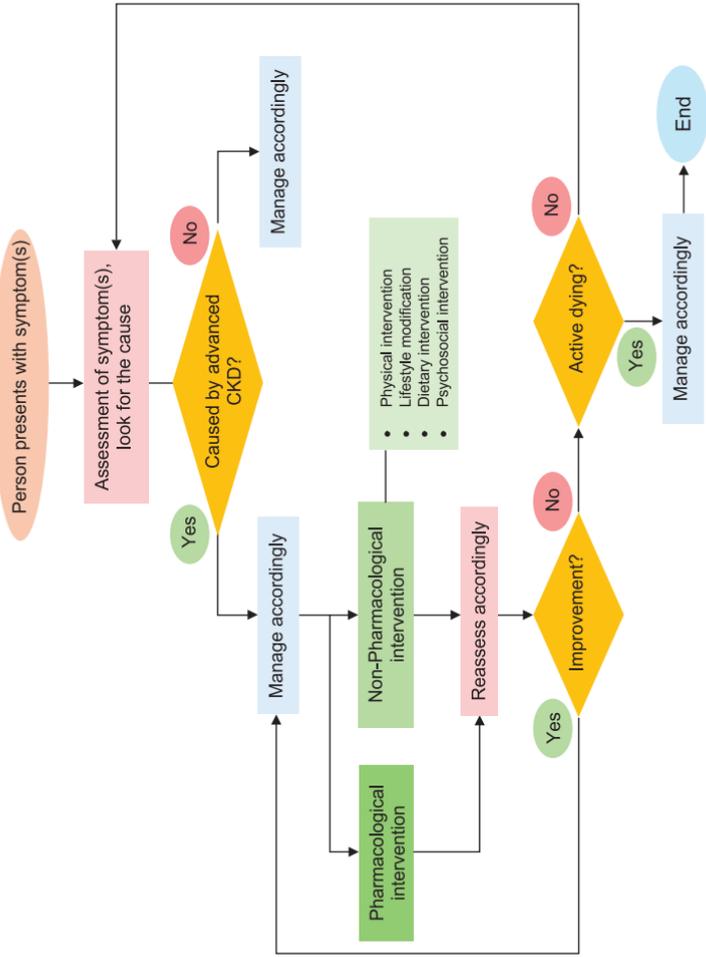
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ALGORITHM 1. CARE PLAN FOR PERSONS WITH ADVANCED CHRONIC KIDNEY DISEASE



ACP: Advance Care Planning
 CKM: Conservative kidney management
 CKD: Chronic kidney disease
 HD: Haemodialysis
 KRT: Kidney replacement therapy
 KSC: Kidney Supportive Care
 NGO: Non-government organisation
 PD: Peritoneal dialysis
 SDM: Shared Decision-Making
 *CKD with multiple co-morbidities and/or life-limiting illnesses may require earlier ACP discussions
 **Decision on KRT or CKM should be in consultation with nephrologist (CKD stage at referral is subjected to availability of speciality/local resources)
 ***Carer burnout, uncontrollable symptoms, lack of community support etc.

ALGORITHM 2. MANAGEMENT OF SYMPTOMS FOR PERSONS WITH ADVANCED CHRONIC KIDNEY DISEASE RECEIVING CONSERVATIVE KIDNEY MANAGEMENT



1. INTRODUCTION

Chronic kidney disease (CKD) is one of the contributors to the global burden of serious health suffering. An estimated of 850 million people are affected worldwide.¹ The prevalence of CKD in Malaysia was 15.48% in 2018, an increase from 9.07% in 2011.² Advanced CKD typically refers to stage 4 - 5 CKD defined based on an estimated glomerular filtration rate (eGFR) <30 ml/min/1.73 m².³ Persons with advanced CKD will need to make decisions on treatment options e.g. kidney transplantation, dialysis or conservative care.⁴ These highly individualised decisions are made collaboratively by patients, families and nephrologists through shared decision-making (SDM).^{5,6} Initiatives are made to build programmes integrating supportive care services into the management of CKD.^{7,8}

Kidney Supportive Care (KSC) is “an approach that aims to improve the quality of life for people for whom kidney disease, either directly or indirectly, substantially impacts their well-being, treatment options, or access to care, and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual”.⁹ The supportive care should be provided throughout the trajectory of the journey of persons with CKD.¹⁰

The trajectory of persons with CKD is unpredictable and palliative care needs are largely unmet.^{11, 12} The National Institute for Health and Care Excellence (NICE) guidelines defined end of life as the last year of life.¹³ However, a systematic review of literature defines features for end of life, terminally ill, and terminal care as “life-limiting disease with irreversible decline and expected survival in terms of months or less”. Recognising the active dying phase (hours or days of survival) is important to address physical and emotional challenges that patients and families face.¹⁴

Figure 1 illustrates the concept of kidney supportive care.

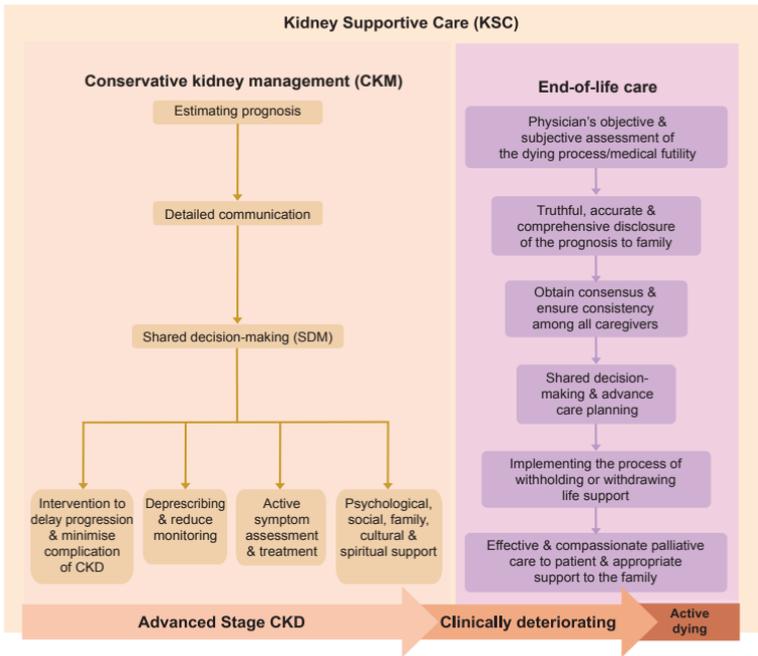


Figure 1: Relationship between kidney supportive care (KSC), conservative kidney management (CKM) and end-of-life care in advanced CKD.

Adapted: Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Int.* 2024;105(4S): S117-S314.

This is the first CPG on conservative kidney management in advanced CKD. Treatment goals and recommendations are clearly stated to ensure that all patients receive appropriate and holistic care. Management of advanced CKD needs to be delivered by multidisciplinary healthcare providers. This CPG will be arranged in accordance to symptoms, as this will guide delivery of person-centred care.

2. PROGNOSTIC ASSESSMENT

There is no consensus on the use of prognostication tools for persons with CKD stage 4 and 5 who choose dialysis or non-dialysis. However, several general clinical tools have been used in palliative care and CKD e.g. Kidney Failure Risk Equation (KFRE)^{74 - 75} and Supportive and Palliative Care Indicators Tool (SPICT™).^{76 - 77} These tools may identify persons with deteriorating health due to advanced, life-threatening conditions who will benefit from supportive care, independent of disease prognosis.

Factors specific to persons with CKD that would guide clinicians to consider CKM include:⁹

- poor quality of life (QoL), including severe physical or psychosocial suffering
- frailty with poor functional status
- multiple co-morbidities, e.g. severe heart failure, advanced age (>80 years)
- severe malnutrition
- medical condition that impedes the technical process of dialysis e.g.
 - poor cooperation (e.g. advanced dementia)
 - medically unstable (e.g. profound hypotension)
 - concomitant life-limiting illness (e.g. advanced cancer)

A large systematic review of 41 cohort studies on long-term outcomes among patients with advanced CKD who chose CKM showed that most patients (mean age ranged from 60 - 87 years) survived several years and experienced sustained QoL until late in the illness course. However, there was substantial heterogeneity in the study designs and outcome measurements.^{15, level II-2} There was also no mention of quality assessment of the studies.

- No prognostic assessment tool is currently available to guide decisions regarding CKM.

3. PLANNING COMPONENTS

In management of advanced CKD, education and SDM are key to optimising outcomes and slowing progression the disease. Educating patients on their condition, lifestyle changes and treatment options empowers engagement, while equipping healthcare professionals with evidence-based guidance ensures individualised care. SDM aligns treatment with patient values, fostering trust, adherence and improved QoL.

3.1. Awareness and Education

CKM should be planned and incorporated into the management strategies of all persons with CKD. Awareness and education to inform health expectations with and without kidney replacement therapy (KRT) are important aspects to be addressed. Factors that influence the selection of CKM can be divided into:^{16, level III}

- patient-related -
 - awareness and perceptions of non-dialysis and dialysis
 - beliefs about survival
 - preferred treatment outcomes
 - influence of family/caregivers and clinicians
- clinician-related -
 - perceptions of CKM as 'non-interventional'
 - perceptions of clinician's role in the decision-making process
 - confidence and ability to initiate sensitive treatment discussions
- organisational-related -
 - relationships with and involvement of other healthcare professionals
 - time constraints
 - limited clinical guidance provided by the organisation

3.2. Kidney Supportive Care

The key considerations for KSC include:⁹

- integration into kidney care throughout all stages of CKD; made available for all persons with advanced CKD
- prioritisation of health-related care according to individual preferences
- incorporation of culturally sensitive SDM
- recognition that individuals have physical, psychosocial and spiritual needs

A systematic review on persons with CKD (including those on dialysis) reported that KSC interventions were effective in improving patient outcomes, especially in end-of-life care and symptom management.^{17, level I}

Refer to **Appendix 3a on Advance Care Planning for Chronic Kidney Disease Patients (English Version)** or **3b for Malay Version**.

Recommendation 1

- Patients, caregivers and healthcare providers should be educated on conservative kidney management options for advanced chronic kidney disease (CKD).
- All persons with advanced CKD with decision for non-dialysis should receive conservative kidney management.*

*Refer to yellow box below.

- CKM is a treatment option other than KRT (transplantation and dialysis). It is a component of KSC.
- Core components of CKM for advanced CKD include:^{9; 4}
 - advance care planning (ACP) and detailed communication including estimating prognosis
 - SDM
 - interventions to delay disease progression
 - measures to minimise risks of AEs
 - management of symptoms
 - management of medical complications
 - crisis planning
 - spiritual care
 - integration with community services
 - end-of-life care considerations
 - bereavement

3.3. Shared Decision-Making

SDM is defined as a collaborative discussion involving patients, caregivers and clinicians.^{18, level III} This process should be conducted in an appropriate environment and time-frame. The discussion is to address the following:

- eliciting patient's and caregiver's concerns
- estimating prognosis
- establishing priorities
- deliberating options and making decisions
- creating a holistic care plan
- clarifying and confirming the understanding of all the above

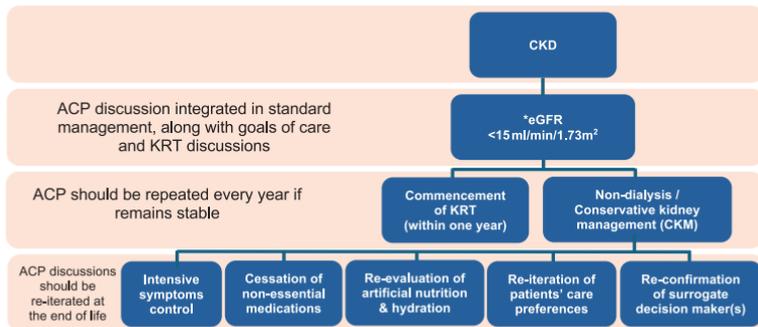
A study demonstrated that successfully conducted SDM processes resulted in increased patient's self-efficacy in making decisions and decreased decisional conflict.^{19, level II-1}

ACP in CKD is a process to explore patients' preferences and wishes for future care, including end-of-life preferences.^{20, level III} Timely ACP and palliative care is a necessary approach to be integrated into clinical management of persons with CKD.²¹

Implementation of ACP needs:

- training for health care professionals that addresses concerns, optimises skills and clarifies processes
- documentation and processes that are simple, individually-tailored, culturally appropriate and involvement of caregivers

ACP discussions need to be performed at different stages of CKD. CKD with multiple co-morbidities and/or life-limiting illnesses may require earlier ACP discussions. This is outlined in the diagram below:^{22, level II}



*CKD with multiple co-morbidities and/or life-limiting illnesses may require earlier ACP discussions

Figure 2. Timeline for ACP discussions

Adapted: Ministry of Health Malaysia. Advance Care Planning A Guide for Healthcare Practitioners in Malaysia. Putrajaya: MoH; 2024.

Recommendation 2

- Shared decision-making and advance care planning should be incorporated in the management for all persons with advanced chronic kidney disease.

3.4. Ethics

Choosing not to initiate dialysis should not be construed as abandonment. Navigating these decisions require an inclusive, person-centred approach. This involves open dialogue between healthcare professionals, patients, and families to identify the goals of care, engage with clinical evidence, and reach a shared understanding of the risks and benefits of available options.²³

Four ethical principles are beneficence, nonmaleficence, respect for autonomy and justice serve as foundational guides in clinical decision-making.²⁴ The application of ethical principles in clinical medicine can be organized as follows:

- medical indications (beneficence and nonmalifience)^{25, level III}
 - deprescribing^{26, level III}
 - reduce monitoring^{27, level III}
 - patient preferences (respect for autonomy)^{25, level III}
 - paternalistic practices vs person-centred care^{28, level III}
 - follow-up and monitoring^{27, level III}
- quality of life vs survival (beneficence, nonmalifience and respect for autonomy)^{25, level III}
 - avoiding futile treatment^{23, level III}
- contextual features (justice and fairness)^{25, level III}
 - accessibility to quality CKM^{23, level III}

Ultimately, ethical decision-making in CKM must be dynamic, compassionate, and responsive to each person's unique trajectory and preferences. Clinicians should be supported to engage in these conversations with confidence, cultural humility, and a strong grounding in ethical principles.

4. MANAGEMENT OF SYMPTOMS

Persons with advanced CKD may experience a high symptom burden regardless of whether they are on dialysis or not. A meta-analysis showed that significant symptom (fatigue particularly prevalent) and HRQoL burden was associated with CKD (14 studies, 4,139 participants: 70%, 95% CI 60 to 79) and those receiving dialysis (21 studies, 2,943 participants: 70%, 95% CI 64 to 76).^{29, level III}

Persons with advanced CKD who present with symptoms and signs require assessment to find the underlying aetiology and be treated accordingly using non-pharmacological and pharmacological interventions.

Recommendation 3

- The management of symptoms in persons with advanced chronic kidney disease receiving conservative kidney management should be tailored to the person, with a focus on identifying and addressing any underlying causes using non-pharmacological and pharmacological approaches.

This CPG discusses the treatment based on symptoms commonly presented in persons with advanced CKD. Refer to **Appendix 4 on Suggested Medication Dosages and Adverse Effects (AEs)**.

4.1. Fatigue/Lethargy

Fatigue or lethargy is a non-specific symptom associated with complications of CKD. Other factors may also contribute to this symptom e.g. AEs of medications, co-morbidities and the impact of aging.

a. Anaemia-related fatigue

A common cause of fatigue in persons with CKD is anaemia. The common cause of this condition is iron deficiency. However, other causes of anaemia should also be addressed.

Iron supplementation is important to be considered before initiating erythropoiesis-stimulating agents (ESA). It will likely reduce the ESA requirement. KDIGO recommends initiating iron supplementation in persons with CKD not on dialysis when:³⁰

- ferritin <100 ng/mL (<100 µg/L) and transferrin saturation (TSAT) <40% or
- ferritin ≥100 ng/mL (≥100 µg/L) and <300 ng/ml (<300 µg/L), and TSAT <25%

The choice of iron administration route [oral or intravenous (IV)] should align with the persons' values and preferences.

In person with CKD not receiving dialysis, ESA initiation based on haemoglobin (Hb) level should be individualised. For most individuals, the level should be between 8.5 and 10.0 g/dL (85 - 100 g/L) in the presence of symptoms. The initial dose of ESA should be determined by the Hb concentration, body weight and clinical circumstances of the person.³⁰ Refer to **Appendix 4** for **Suggested Medication Dosages and AEs**.

A systematic review of non-dialysis patients with CKD-related anaemia showed improvements in energy and physical functions with ESA treatment compared with the control group.^{31, level I}

There is limited evidence on the use of non-pharmacological interventions in the management of anaemia in persons with CKD receiving CKM. A randomised controlled trial (RCT) in persons with Stage 4 CKD compared the effects of a home-based exercise programme on physical functioning and health-related quality of life (HRQoL) against control (no specific intervention). The study showed that a 6-month home-based exercise programme (unsupervised individualised aerobic exercise thrice weekly and resistance exercise twice weekly) improved aerobic capacity and HRQoL in the intervention group compared with control ($p < 0.001$ and $p = 0.007$ respectively).^{32, level I}

Other non-pharmacological approaches e.g. massage, reflexology and yoga, improve fatigue in persons on dialysis.^{33, level I}

There is limited data on the dietary intake of iron-rich foods (i.e. animal organs, cockles, etc.) in CKD. A diet high in iron is often poorly tolerated by persons with CKD³⁴ as iron absorption in the gut is reduced^{35, level III} and the presence of phosphate binders taken with meals further inhibits its absorption.^{36, level III}

- There is insufficient evidence to support the consumption of iron-rich food to improve CKD anaemia.

Recommendation 4

- Persons with advanced chronic kidney disease receiving conservative kidney management with fatigue should be evaluated for anaemia and treated accordingly.
 - Iron supplementation should be considered as initial therapy for those with iron deficiency.

b. Other causes of fatigue

Other causes of fatigue should be considered and managed accordingly. Some of the common causes are:³⁷

- co-morbidities e.g. diabetes mellitus, cardiovascular disease, depression, anxiety, cancer
- metabolic disorders e.g. metabolic and lactic acidosis, inflammatory conditions, hyperphosphataemia
- malnutrition e.g. sarcopenia, protein-energy-wasting (PEW)
- hypoxia
- AEs of drug e.g. antihistamines, opioids, anticonvulsants

An RCT that looked into the effectiveness of an energy conservation education intervention for persons with kidney failure receiving haemodialysis (EVEREST) showed a significant reduction at week 8 compared to the control group in:^{38, level I}

- fatigue severity using the fatigue symptom inventory (MD= -1.88, 95% CI -2.36 to -1.40)
- fatigue interference (MD = -1.52, 95 % CI -2.02 to -1.02)
- number of fatigue days (MD = -1.12, 95 % CI -1.60 to -0.64)

Refer to **Appendix 5 for Energy Conservation Strategies.**

4.2. Sleep Disturbances

The prevalence of sleep disturbances in persons with advanced CKD opting for CKM ranged between 20% to 83%.³⁹

The possible contributing factors to sleep disturbances [e.g. restless leg syndrome (RLS), pruritus, pain, breathlessness, AEs of medications, mood disorders] should be identified and managed accordingly.^{40, 21}

If the person has concomitant symptoms (e.g. neuropathic pain, RLS, uraemic pruritus), consider low dose of gabapentin or pregabalin. If it is ineffective, consider mirtazapine, zopiclone and melatonin.⁴⁰

There is no retrievable evidence in managing sleep disturbances in persons with advanced CKD receiving CKM. A narrative review of sleep disturbances showed that cognitive behavioral therapy for insomnia (CBT-I) (refer **Appendix 6**) has been used as first-line therapy in general population. However, the effectiveness may be lower in patients receiving dialysis.^{41, level III}

KDIGO 2024 guidelines suggests basic sleep hygiene, exercise, optimal positioning when sleeping, removal of dietary or other stimulants (e.g. caffeine) to manage sleep disturbances among persons with CKD.²¹

Acupressure has demonstrated effectiveness in alleviating sleep disturbance in CKD patients.^{33, level I}

- In local settings, nonbenzodiazapines (z-drug) or benzodiazepines are commonly used to manage sleep disturbances among persons with CKD after addressing the possible contributing factors.

4.3. Pain

In a large systematic review, 59.8% of persons with CKD managed conservatively without dialysis experienced chronic pain.^{42, level I} An important cornerstone of pain management is the holistic understanding of pain in terms of the underlying cause, intensity and progression.

The World Health Organization (WHO) analgesic ladder emphasises the importance of careful selection of analgesia, beginning with non-opioids and subsequently progressing to opioids, with dose adjustments made depending on the patient's kidney function. Non-steroidal anti-inflammatory drugs (NSAIDs) should be avoided in this population and for opioids, fentanyl is the preferred choice.⁴⁰ Fentanyl should be initiated after consultation with practitioners experienced in pain management.

If neuropathic pain is present, it should be managed using adjunctive therapy e.g. anticonvulsants (gabapentin, pregabalin, carbamazepine) and/or antidepressants (amitriptyline).⁴⁰ Refer to **Appendix 4** for **dose adjustment**.

In terms of non-pharmacological measures, there was no evidence in the CKM group. A systematic review showed that music and yoga therapies were effective for pain reduction in persons with advanced CKD on dialysis.^{33, level I}

Other therapies have been suggested for pain in dialysis population which include physical therapies (massage, acupressure and acupuncture) and behavioural therapies (cognitive behavioural therapy, biofeedback, relaxation techniques, psychotherapy).⁴⁰

Recommendation 5

- The management of pain in persons with advanced chronic kidney disease receiving conservative kidney management should follow World Health Organization Step Ladder pain management.
 - Non-steroidal anti-inflammatory drugs should be avoided.
 - Fentanyl is the preferred choice of opioid therapy.*

*It should be initiated after consultation with practitioners experienced in pain management.

- Morphine immediate-release (IR) formulations may still be used in persons with kidney impairment using renal dose adjustment; close monitoring for signs of toxicity e.g. sedation or respiratory depression is recommended.

4.4. Dyspnoea

Dyspnoea is a common symptom experienced by persons with advanced CKD. The prevalence and severity of dyspnoea is difficult to estimate but its impact is thought to be dependent on different stages of kidney disease. The causes of dyspnoea need to be determined in order to be managed accordingly. The different causes of dyspnoea include anaemia, fluid overload, severe metabolic acidosis and cardiorespiratory diseases.^{43, level I}

An evidence-based guideline recommends if fluid overload has been determined as the main cause of dyspnoea, a trial of high dose loop diuretics i.e. frusemide may be considered.⁴⁰ A low dose of opioids can be used in cases of dyspnoea towards end-of-life.⁴⁰ Short acting benzodiazepines i.e. lorazepam may be used adjunctively at low dose and titrated upwards according to patient's response and tolerability.^{44, level III}

There is no strong evidence on the use of benzodiazepines for dyspnoea in persons with CKD receiving non-dialysis care. A Cochrane systematic review found that benzodiazepines had no proven benefits or drawbacks for treating dyspnoea in patients with advanced diseases (advanced stages of cancer, chronic obstructive pulmonary disease, chronic heart failure, motor neurone disease and idiopathic pulmonary fibrosis). Benzodiazepines have in fact been used as a second- or third-line treatment, when opioids and non-pharmacological measures have failed to control breathlessness.^{Simon ST et al., 2016, level I}

In terms of non-pharmacological measures, keeping patients in an upright position, using a handheld fan blown across the face and supplemental oxygen therapy with pursed lip breathing are some measures that can be pursued for symptomatic relief of breathlessness.³⁹

- In persons with advanced CKD receiving CKM, causes of dyspnoea should be determined and managed accordingly; tailored to individual's preferences.
- CPG DG suggests that persons with advanced CKD persons receiving CKM with hypervolemia-related dyspnoea can be addressed using these practical strategies:
 - Assess understanding of and adherence to fluid and sodium restrictions.
 - Review health literacy (assess food label comprehension for sodium content). Refer to **Appendix 7 for Tips to reduce dietary sodium/natrium intake.**
 - Review food choices and assist with shopping list/food swaps.
 - Encourage non-salt spices.
 - Assist with limiting fluid intake (cup size, spreading fluid throughout the day, ice).

4.5. Uraemic Pruritus

The prevalence of uraemic pruritus in persons with CKD was approximately 46%.²¹

In a retrospective cohort study on persons with advanced CKD receiving CKM vs haemodialysis, gabapentin:^{45, level II-2}

- significantly reduced pruritus at different visits compared with baseline based on the Palliative Care Outcome Scale - Total Symptom; however, there was no significant difference in the outcome between the two groups
- significantly caused higher AEs in the conservative group (47.1% vs 13.3%); the most common was drowsiness, followed by dizziness and fatigue

In a large Cochrane systematic review, Gamma-Aminobutyric Acid (GABA) analogues (including gabapentin and pregabalin) reduced uraemic pruritus in persons with CKD [SMD in Visual Analogue Scale (VAS) score= -2.14, 95% CI -2.43 to -1.85] compared with placebo. In another comparison, GABA analogues (gabapentin) was slightly more effective in reducing uraemic pruritus compared with antihistamines (SMD= -0.44, 95% CI -0.75 to -0.14). Few mild AEs were reported.^{46, level I} The study population in the review included those on dialysis and the primary papers were of mixed quality.

A systematic review showed difelikefalin significantly improved pruritus intensity in persons on haemodialysis compared with placebo.^{47, level I} However, it is not readily available in Malaysia.

In the presence of xerosis, a trial of emollients can be considered in persons with CKD.^{48, level III}

The KDIGO guidelines recommend topical agents for uraemic pruritus, such as capsaicin cream. In the presence of dry skin, rehydrating emollients can be added.²¹ In local settings, menthol in aqueous cream has been used for pruritus.

An evidence-based guideline recommends the following non-pharmacological interventions for uraemic pruritus:⁴⁰

- appropriate skin care and moisturisers (e.g. baths with lukewarm water, gentle soaps with no fragrances or additives, pat dry and aqueous emollients application)
- avoid scratching - maintain short, smooth fingernails, encourage gentle massage and wear gloves at night

For the non-pharmacological approach, there is no concrete evidence for person with advanced CKD receiving CKM. Nevertheless, acupressure and acupuncture have improved uraemic pruritus in persons receiving dialysis.^{21; 33, level I}

Pruritus worsens with hyperphosphatemia, therefore the amount and source of dietary phosphorus intake and adherence towards phosphate binders (if available) should be assessed and managed.^{49, level III}

Overall evidence of omega-3, omega-6, turmeric, zinc or evening primrose to manage pruritus symptoms in persons with advanced CKD is limited due to methodological weaknesses, potential bias, and a focus primarily on dialysis patients.^{46, level I; 50, level III}

- In local settings, common practices to address pruritus in persons with advanced CKD include:
 - antihistamines
 - emollients in the presence of xerosis
 - reduction in dietary phosphate intake

Recommendation 6

- Gamma-Aminobutyric Acid analogues may be used to treat uraemic pruritus in persons with advanced kidney disease receiving conservative kidney management.

4.6. Neurological Symptoms

Neurological symptoms usually appear in active dying phase. Refer to **Chapter 7 on Active Dying**.

4.7. Restless Leg Syndrome

Restless legs syndrome (RLS) commonly affects 27% of persons with advanced CKD not on dialysis or transplant.^{29, level III} RLS refers to an irresistible urge to move lower limbs to alleviate unpleasant sensation of legs experienced by the patient which affects patient's QoL.

In a retrospective cohort study on CKD patients receiving CKM and haemodialysis, gabapentin significantly reduced RLS based on Palliative Care Outcome Scale (POS) - Total Symptom. It was associated with higher AEs in the conservative group as compared with haemodialysis group (47.1% vs 13.3%); most common AEs were drowsiness, followed by dizziness and fatigue.^{45, level II-2}

KDIGO guidelines recommend the following for RLS in persons with CKD:²¹

- lifestyle modifications - exercise, basic sleep hygiene, optimal positioning when sleeping
 - avoidance of certain medications that interfere with the dopamine pathway
 - correction of hyperphosphatemia and iron deficiency/anaemia
- In persons with advanced CKD having RLS, non-pharmacological interventions are preferred.
 - In local settings, gabapentin is used with caution to treat RLS in persons with advanced CKD.

In terms of non-pharmacological approaches, there was no strong evidence on the treatment of RLS in persons advanced CKD receiving CKM. However, oil massages, aromatherapy and reflexology may have some role as it has shown some beneficial effect on dialysis patients.^{33, level I}

4.8. Psychological/Mood Disturbances

Psychological distress is common in people living with CKD stage $\geq 3B$. Depending on the assessment methods undertaken, between 22 - 39% and 19 - 43% of CKD patients experience depression and anxiety, respectively.^{51, level III}

a. Anxiety

There is no strong evidence supporting any intervention for anxiety in persons with advanced CKD receiving non-dialysis care. However, a systematic review on persons with CKD stage 4 and 5 receiving dialysis showed that anxiety symptoms were reduced by music and spiritual therapies.^{33, level I}

b. Depression

There is no strong evidence for non-pharmacological interventions for depression in persons with advanced CKD receiving CKM. However, KDIGO guidelines recommend the following for persons with CKD:²¹

- exercise
- acupuncture
- cognitive behavioural therapy
- address contributing factors (e.g. pain, pruritus and mood disorders)

Psychosocial interventions provide social, emotional or psychological support without medication. A meta-analysis of such interventions [e.g. cognitive-behavioural therapy (CBT), exercise and counselling] in dialysis patients showed mixed effects on depression.^{52, level I}

A Cochrane systematic review looked on psychosocial interventions versus usual care or a second psychosocial intervention for preventing and treating depression in patients with end-stage kidney disease (ESKD) treated with dialysis. Findings showed that CBT reduced depressive symptoms compared with usual care (MD= -6.1, 95% CI -8.63 to -3.57). The evidence were of moderate certainty based on GRADE assessment.^{53, level I}

In an RCT on persons with stage 3, 4, or 5 non-dialysis-dependent CKD and major depressive disorder, compared with placebo, sertraline showed no significant difference in:^{54, level I}

- 16-item Quick Inventory of Depression Symptomatology-Clinician Rated score change (between-group difference=0.1, 95% CI -1.1 to 1.3)
- Kidney Disease Quality of Life Survey (between-group difference=0, 95% CI -10.0 to 0)

However, AEs were higher in sertraline group e.g. nausea and vomiting (between-group difference=12.3%, 95% CI 1.9 to 22.6), diarrhoea (between-group difference=10.3%, 95% CI 2.7 to 17.9) as compared with placebo.

KDIGO guidelines recommend selective serotonin reuptake inhibitors, serotonin-norepinephrine re-uptake inhibitors, atypical antidepressants (bupropion) and tricyclic antidepressants for depression in persons with advanced CKD on dialysis.²¹

Recommendation 7

- In persons with advanced chronic kidney disease receiving conservative kidney management with depression and/or anxiety:
 - non-pharmacological interventions e.g. cognitive-behavioural therapy and lifestyle modifications may be considered
 - selective serotonin reuptake inhibitors or serotonin-norepinephrine re-uptake inhibitors may be used

4.9. Gastrointestinal Symptoms

Gastrointestinal (GI) symptoms are common in persons with advanced CKD receiving CKM and can impact their QoL. These symptoms can range from mild to severe and may include dry mouth, anorexia, nausea and constipation. The prevalence and severity of GI symptoms tend to increase as the disease progresses.

a. Dry mouth

The prevalence of dry mouth among persons with CKD was approximately 41%.^{29, level III} The causes of dry mouth include mandibular breathing, AEs of medications and oral thrush.

- The CPG DG suggests that dry mouth can be addressed using the following practical strategies:
 - Limit sodium intake.
 - Promote saliva production by using:
 - artificial saliva
 - salivary enzyme
 - natural food acids (e.g. lemon or lime juice)
 - hard mints, sour lollipops or frozen fruits
 - chewing gum
 - Rinse mouth regularly with plain water.*
 - In presence of tongue plaque, sodium bicarbonate mouth wash may be used.

*Rinsing with alcohol-contained mouth wash may further worsen dry mouth.

b. Anorexia

The prevalence of anorexia is estimated to be 40 - 50% among patients with kidney failure.^{49, level III}

There is no retrievable evidence on the use of specific enteral formulations (e.g. complete energy-dense, low electrolyte, etc.) and in persons with advanced CKD receiving CKM.

There is insufficient evidence to support the use of appetite stimulants (e.g. megestrol acetate and corticosteroids) to improve anorexia in persons with advanced CKD receiving CKM. Nevertheless, megestrol acetate has been used for anorexia in patients receiving palliative care which included end-stage kidney disease.^{55, level I}

- The CPG DG suggests that in persons with advanced CKD receiving CKM, anorexia can be addressed using these practical strategies:
 - liberalising dietary restrictions
 - small and frequent meals
 - nutrient fortification in food and beverages

c. Nausea and vomiting

Nausea and vomiting are common symptoms in persons with advanced CKD. It affects approximately 46% of this population due to uraemia, drugs (e.g. opioids, antibiotics, anticonvulsants), diabetic gastroparesis and/or uraemic gastropathy.^{44, level III}

An evidence-based CPG recommends the following for patients with CKD stage 5 who are unlikely to benefit from dialysis and/or who choose a non-dialysis care option for nausea and vomiting:⁴⁰

- first line: ondansetron
- second line: metoclopramide
- third line: olanzapine/haloperidol

In local settings, metoclopramide and haloperidol are used to manage nausea and vomiting in this population.

- The practical strategies suggested for nausea and vomiting in persons with advanced CKD receiving CKM include:^{49, level III}
 - small and frequent meals
 - avoidance of strong smells
 - opting for dry, bland and room temperature food
 - incorporation of ginger* into food and beverages

*Caution: Excessive ginger intake especially in powder form may increase dietary potassium intake.^{56; 57, level III}

Recommendation 8

- In persons with advanced chronic kidney disease receiving conservative kidney management, ondansetron, metoclopramide, haloperidol or olanzapine may be used for nausea and vomiting.

d. Constipation

The prevalence of constipation in persons with advanced CKD receiving CKM varied between 4.5% and 38%. This symptom may be due to dietary fibre and fluid restriction, sedentary lifestyle, co-morbidities (e.g. diabetes mellitus), AEs of medications (e.g. phosphate binders and iron supplements) and metabolic disturbances (e.g. hyperkalaemia).^{58, level III}

In general, non-pharmacological interventions e.g. dietary and lifestyle modifications are first-line approaches for constipation.⁵⁹ The suggested modifications include:^{49, level III; 58, level III}

- dietary
 - adequate fibre intake* from whole fruit and vegetable
 - adequate fluid intake (within fluid restriction)
- lifestyle
 - increase physical exercise

*Fibre-enriched products may contain significant amounts of sodium, phosphate or potassium which may not be suitable for all kidney patients, especially those with advanced-stage disease.^{60, level III}

Laxatives are given for patients who do not respond to first-line approaches.⁵⁹ The following classes of laxatives have been used in CKD:^{58, level III}

- saline (e.g. magnesium hydroxide, sodium phosphate*)
- osmotic agents (e.g. lactulose, polyethylene glycol)
- stool softeners (e.g. sodium docusate)
- lubricants** (e.g. mineral oil, glycerin)
- stimulate/irritative laxatives (e.g. senna, bisacodyl)

*Sodium phosphate enema should be used cautiously due to its high phosphate load.

**Oral liquid paraffin is not recommended for the elderly because of the risk of aspiration and lipid pneumonitis.

Recommendation 9

- In persons with advanced chronic kidney disease receiving conservative kidney management having constipation:
 - non-pharmacological interventions (dietary and lifestyle modifications) should be the first-line approach
 - pharmacological intervention (laxatives) may be used as a second-line approach

5. NUTRITION

Nutrition management in persons with advanced CKD aims to prevent premature death from malnutrition and minimise food-related symptom burden. This will improve QoL while addressing both nutritional needs and limited kidney function. Patients' and caregivers' assessment and education on renal nutrition are advised.

5.1. Nutrition Screening

Nutrition screening in advanced CKD is vital for early detection of malnutrition and timely interventions. KDIGO guidelines recommend to screen people with CKD 4 - 5, aged >65 or with symptoms e.g. involuntary weight loss, frailty or poor appetite, twice annually for malnutrition using a validated nutritional assessment tool.²¹

- To screen nutrition status in advanced CKD with symptoms, the following validated nutritional assessment tools have been used e.g.:
 - 7-Point Subjective Global Assessment
 - Malnutrition-Inflammation Score
 - Mini Nutrition Assessment

5.2. Protein and Energy

Two meta-analyses on adults with CKD significantly showed:

- low protein diet (<0.8 g/kg body weight/day) compared with high protein diet reduced risk of progression to ESKD and metabolic complications^{61, level I}
- very-low-protein diet (<0.4 g/kg body weight/day) compared with low protein diet was associated with greater preservation of kidney function and reduced rate of progression to ESKD^{61, level I}
- very-low-protein diet supplemented with keto analogues compared with normal diet delayed progression of CKD effectively without causing malnutrition^{62, level I}

In a systematic review of clinical trials on CKD patient stage 3 - 5 not on dialysis, diet incorporating at least 50% protein from plant-based sources for ≥1 week showed no change or decrease in kidney function.^{63, level I}

The KDIGO guidelines outline the following recommendations in adults with CKD stage 3 - 5:²¹

- protein intake of 0.8 g/kg body weight/day
- avoidance of high protein intake (>1.3 g/kg body weight/day)
- for patients willing to be on a very low-protein diet (0.3 - 0.4 g/kg body weight/day) supplemented with essential amino acids

or ketoacid analogues (up to 0.6 g/kg body weight/day), close supervision is required

- in metabolically unstable people (older adults with underlying conditions i.e. frailty and sarcopenia), low- or very low-protein diets should not be prescribed

European Society for Clinical Nutrition and Metabolism (ESPEN) Guidelines recommends the following protein requirements for hospitalised persons with CKD:⁶⁴

- without acute/critical illness: 0.6 - 0.8 g/kg body weight/day
- with acute/critical illness, not on KRT: start with 1 g/kg body weight/day and gradually increase up to 1.3 g/kg body weight/day if tolerated
- overfeeding should be avoided to achieve a positive nitrogen balance or minimise an existing negative nitrogen balance

KDOQI guidelines recommend an energy intake of 25 - 35 kcal/kg of body weight/day for all metabolically stable adults with CKD to maintain normal nutritional status. The following factors affect the energy requirement:⁶⁵

- age
- gender
- physical activity level
- body composition
- weight goals
- CKD stage
- concurrent illnesses or inflammation

Recommendation 10

- For stable persons with advanced chronic kidney disease (CKD) receiving conservative kidney management (CKM), the following should be considered:
 - protein intake of 0.6 - 0.8 g/kg body weight/day
- For hospitalised persons with advanced CKD receiving CKM, protein and energy intake should be individualised.

Refer to **Appendix 8** for **Dietary Protein Intake Recommendation**.

5.3. Electrolytes and Fluid

a. Sodium

In advanced CKD persons receiving non-dialysis care, managing dietary sodium intake is essential to prevent fluid retention, control blood pressure (BP) and improve quality of life. Proper sodium restriction helps reduce complications and supports overall kidney function.

Two meta-analyses on adults with CKD receiving non-dialysis care showed:

- low salt intake significantly reduced systolic BP (SBP), diastolic BP (DBP), proteinuria and albuminuria compared with high salt intake^{66, level I}
- sodium-specific medical nutrition therapy significantly reduced urinary sodium excretion, ambulatory SBP and ambulatory DBP compared with control^{67, level I}

The KDIGO guidelines highlight the following for persons with CKD:²¹

- sodium intake <2 g/day (or <90 mmol of sodium per day or <5 g of sodium chloride per day)
- dietary sodium restriction is usually not appropriate for patients with sodium-wasting nephropathy

The KDIGO guidelines highlight the following for persons with CKD:²¹

- use of salt substitutes that are rich in potassium may not be appropriate for persons with advanced CKD because of the potential for hyperkalaemia

Refer to **Appendix 7 for Tips to Reduce Sodium/Natrium Intake.**

b. Potassium

KDIGO guidelines advise limiting the consumption of foods high in bioavailable potassium (e.g. processed foods) for individuals with CKD stage 3 - 5 who have a history of hyperkalaemia or as a preventive measure during periods when the risk of hyperkalaemia may be elevated.²¹

c. Phosphorus

KDOQI guidelines recommend adjusting dietary phosphorus intake to maintain serum phosphate levels in normal range in adults with CKD stage 3 - 5.⁶⁵

d. Fluid

The management of fluid intake in persons with advanced CKD receiving non-dialysis care is essential to prevent fluid overload and reduce symptom burden. Personalised fluid recommendations help to optimise patient's comfort and minimise complications.

There is no retrievable evidence for exact amount of fluid restriction in CKD stage 4 - 5 patients for non-dialysis care.

Recommendation 11

- In persons with advanced chronic kidney disease receiving conservative kidney management:
 - sodium intake should be <2 g/day
 - dietary potassium, phosphorus and fluid intake should be individualised

5.4. Specific Diet

KDIGO guidelines recommend the following in patients with CKD:²¹

- adopt healthy and diverse diets with a higher consumption of plant-based foods than animal-based foods and a lower consumption of ultra-processed foods
- consider a plant-based “Mediterranean-style” diet in addition to lipid-modifying therapy to reduce cardiovascular risk
- limit intake of alcohol, meats and foods with high-fructose corn syrup for hyperuricaemia

KDOQI guidelines recommend the following:⁶⁵

- in adults with CKD stage 1 - 5 not on dialysis, with or without dyslipidaemia, a Mediterranean Diet may improve lipid profiles
- in adults with CKD stage 1 - 4, increased fruit and vegetable intake may decrease body weight, BP and net acid production

Recommendation 12

- Persons with advanced chronic kidney disease receiving conservative kidney management should:
 - consume a balanced diet with a higher proportion of plant-based foods
 - limit consumption of ultra-processed foods

5.5. Supplements

KDIGO guidelines recommend reviewing and limit use of over-the-counter medicines and dietary or herbal remedies that may be harmful to persons with CKD.²¹

KDOQI 2020 guidelines recommend the following for adults with CKD stage 3 - 5:⁶⁵

- a minimum 3-month trial of oral nutritional supplements to improve nutritional status if dietary counselling alone does not achieve sufficient energy and protein intake for those at risk or with protein-energy wasting
- prescribe 2 g/day Long Chain Omega-3 Polyunsaturated Fatty Acids (LC n-3 PUFA) to lower serum triglyceride levels

Recommendation 13

- The use of dietary or herbal remedies or supplementations in persons with advanced chronic kidney disease receiving conservative kidney management should be limited as it may be harmful.
- If available, consult a trained dietitian in renal nutrition about dietary modifications related to protein, energy, sodium, potassium, phosphorus and fluid intake, tailored to individual needs.

6. FOLLOW-UP AND INVESTIGATIONS

6.1. Follow-up

KDIGO guidelines recommend patient-centered, multidisciplinary team-based integrated care in persons with CKD. Supportive care in persons with advanced CKD focuses in improving health-related QoL.²¹

As the disease progresses, persons with advanced CKD receiving CKM will experience more symptoms and complications. Hence, it is important to assess and address their symptoms during follow-up. The affected persons should be provided with the services for ACP and palliative care.²¹

There is no strong evidence on tools or methods to assess the symptoms and QoL for persons with advanced CKD receiving CKM. However, CPG DG suggests that a few tools that may help in the assessment include Integrated Palliative Outcome Scale - Renal (IPOS-Renal) and Edmonton Symptom Assessment System Revised (ESAS-r). Refer to **Appendix 9a - 9d on IPOS-Renal Staff and Patient Versions**. ACP should be repeated yearly if the disease remains stable and when it reaches the stage of end-of-life.^{22, level III}

Recommendation 14

- The implementation of advance care planning should be ensured during follow-up in persons with advanced chronic kidney disease receiving conservative kidney management.

6.2. Blood Investigations

Blood investigations in persons with advanced CKD receiving non-dialysis care is individualised based on their condition and life expectancy. For those with anaemia on iron therapy, haemoglobin (Hb), ferritin and transferrin saturation (TSAT) can be tested every three months.³⁰

- CPG DG suggests that for persons with advanced CKD receiving CKM:
 - routine blood investigations (Hb, renal profile, serum albumin, calcium, phosphate, HbA1C for diabetics, lipid profiles, etc.) may be done 3- to 6-monthly
 - decision for blood investigations at the end of life should be individualised and considered only if it will change management.

6.3. Caregiver Support

Caregivers play a vital role in caring for persons with advanced CKD opting for non-dialysis care. It is equally important to provide support for them as well.

In a mixed-methods systematic review on the experiences among the caregivers of persons with advanced CKD receiving CKM, the quantitative analysis showed that they had caregiver burden with similar impact on QoL compared with those caring for persons on dialysis. The thematic synthesis of the qualitative studies revealed the following issues:^{68, level I}

- gaps in understanding the concept of CKM
 - need for involvement in the decision for CKM
 - need to identify available supports
 - uncertainty about the future and negotiating deterioration and dying
 - burden of care impacting on QoL
- Caregivers of persons with advanced CKD receiving CKM:
 - experience high caregiver burden which may affect their QoL
 - require informational, medical and psychosocial support from healthcare providers

Refer to **Appendix 10** for **Care Giver Training in Renal Palliative Care**.

Refer to **Appendix 11** for **Resources for Caregivers of Persons with Advanced Chronic Kidney Disease** to address caregiver needs.

7. ACTIVE DYING

This chapter addresses persons with advanced CKD receiving CKM whose life expectancy is hours to days. The signs of dying include apnoea periods, Cheyne-Stokes breathing, death rattle, respiration with mandibular movement, terminal delirium, dysphagia of liquids, decreased level of consciousness, palliative performance scale \leq 20%, peripheral sinusitis, urine output over the last 12 hours <100 mL and pulselessness of radial artery.^{14, level III}

Important issues during active dying that need special consideration are:

- clinical assisted-hydration (CAH)^{69, level III}
 - oral fluids - encouraged to take sips of fluid whenever possible
 - decision on CAH should be individualised with communication between patients, caregivers and healthcare providers; this should be documented
- seizure
 - seizure in dying persons with advanced CKD receiving non-dialysis care can be very distressing to the family and carers^{70, level III}
 - there is lack of evidence for pharmacological interventions, however, seizure lasting more than five minutes should be given abortive treatment.^{71, level III}
 - general - during and after the seizure episode, measures can be taken to prevent trauma and complications
 - pharmacotherapy
 - rapidly acting benzodiazepines (lorazepam, diazepam, midazolam) to abort seizure
 - palliative sedation for refractory seizure at the end of life to be delivered by trained healthcare providers
- terminal secretion (death rattle)
 - a common symptom in dying patients^{72, level I}
 - common treatment includes anticholinergic hyoscine butylbromide, atropine, scopolamine or glycopyrronium^{72, level I}
 - no evidence on the superiority of any antimuscarinic drugs vs no treatment^{73, level I}
- terminal delirium^{14, level III}
 - a common symptom when patient is dying
 - 50 - 70% of delirium are hyperactive or mixed subtypes that are characterised by agitation and often associated with hallucinations, delusions and hypervigilance
 - although there is a lack of evidence to support non-pharmacological management orientation cues, hearing or visual aids and sleep enhancement may be used
 - pharmacologically, neuroleptics and benzodiazepines (i.e. haloperidol, olanzapine, lorazepam and chlorpromazine, levomepromazine, quetiapine, risperidone) can be used

- cases of refractory agitated delirium may be referred to palliative care physician

- It is important to establish good symptoms control in the active dying phase as it is crucial to maintain comfort and dignity at the end of life.
- It is paramount to prepare the family/caregivers in facing the persons' active phase of dying. Preparation should be holistic, re-emphasising goals of care aiming for comfort while respecting the persons' values and preferences.

8. IMPLEMENTING THE GUIDELINES

The management of persons with advanced CKD receiving non-dialysis care should be guided by an evidence-based approach, in order to provide quality care to the patients. Several factors may affect the implementation of recommendations in the CPG.

8.1. Facilitating and Limiting Factors

Existing facilitating factors for application of the recommendations in the CPG include:

- wide online dissemination of the CPG to healthcare providers nationwide
- regular scientific meetings/conferences/trainings nationally where updates on advanced CKD may be highlighted
- use of nephrology-related websites e.g. Academy of Medicine, Malaysian Society of Nephrology, National Kidney Foundation, MyBuahPinggang, etc., where reliable and credible information on advanced CKD can be provided to public
- use of palliative care-related website e.g. Malaysian Hospice and Palliative Care Council where reliable and credible information on palliative care be provided to public
- World Kidney Day and World Hospice and Palliative Care Day celebrations and educational activities at various hospital level across country to raise awareness on advanced CKD and its management
- multidisciplinary collaboration in providing holistic management for both persons with advanced CKD and their caregivers

Existing barriers for application of the recommendations of the CPG are:

- existing registry does not capture the data on CKM
- limited awareness, knowledge and expertise on CKM among healthcare providers
- lack of awareness, knowledge and acceptance of CKM among persons with advanced CKD and their caregivers

8.2. Potential Resource Implications

Several issues need to be addressed in the implementation of the CPG on CKM for advanced CKD persons i.e.:

- Lack of awareness and knowledge in healthcare providers, persons with advanced CKD and their caregivers. Hence, advocacy and literacy should be addressed via regular promotions and educational activities.
- No proper syllabus on CKM in medical and allied health training. Thus, education and training should be embedded in both undergraduate and postgraduate programmes.

- Scarcity of data available for persons advanced CKD receiving CKM. The existing National Renal Registry only records patients on KRT. It could be expanded to record the data of persons receiving CKM. This would be extremely useful in planning care and services in the nation.
- Shortage of human resources with expertise in this field in the local setting. It is a major barrier to equitable care and this gap must be addressed.
- Limited funding and infrastructures to provide holistic care nationwide. Hence, integration and implementation of various national strategic plans and policies are crucial.
- Limited indication for certain drugs commonly used in CKM in the national drug formulary. Therefore, indication for usage of these drugs should be reviewed and updated.

Therefore, the recommendations in this CPG require all the above issues to be tackled for successful implementation.

8.3. Clinical Audit Indicators

The following is proposed as clinical audit indicators for the CPG:

- Percentage of persons with advanced CKD receiving CKM with documented ACP = $\frac{\text{Number of persons with advanced CKD receiving CKM with documented ACP in a period}}{\text{Number of persons with advanced CKD receiving CKM in the same period}} \times 100\%$

Implementation strategies will be developed following the approval of the CPG by MoH which will include Quick Reference and Training Module.

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Appendix 1

EXAMPLE OF SEARCH STRATEGY

Clinical Questions: What are the planning components for CKD stage 4 and 5 patients?

- Goals of Care
- Advance Care Planning

1. RENAL INSUFFICIENCY, CHRONIC/
 2. ((chronic kidney or chronic renal) adj2 disease*).tw.
 3. ((chronic kidney or chronic renal) adj2 insufficienc*).tw.
 4. ckd.tw.
 5. KIDNEY FAILURE, CHRONIC/
 6. ((end-stage kidney or end-stage renal) adj2 (disease or failure)).tw.
 7. ((end stage kidney or end stage renal) adj3 (disease or failure)).tw.
 8. ((chronic renal or chronic kidney) adj2 failure).tw.
 9. esrd.tw.
 10. eskd.tw.
 11. esrf.tw.
 12. or/1-11
 13. PATIENT CARE PLANNING/
 14. (care adj1 goal*).tw.
 15. ((nursing care or patient care) adj2 plan*).tw.
 16. "Goals of care".tw.
 17. Advance Care Planning/
 18. ((advance care or advance medical) adj2 plan*).tw.
 19. (advance health care adj3 plan*).tw.
 20. (advance healthcare adj2 plan*).tw.
 21. DECISION MAKING, SHARED/
 22. (shared adj2 decision mak*).tw.
 23. ADVANCE DIRECTIVES/
 24. (advance adj1 directive*).tw.
 25. (attorney adj2 (medical power or healthcare power)).tw.
 26. (contract* adj1 ulysses).tw.
 27. (health care power adj3 attorney).tw.
 28. (psychiatric adj1 will*).tw.
 29. or/13-28
 30. 12 and 29
- limit 30 to (english language and humans and "all adult (19 plus years)")

Appendix 2

CLINICAL QUESTIONS

1. What is the accurate prognostic assessment tool to identify CKD stage 4 and 5 patients for non-dialysis care/palliative care?
2. What are the planning components for CKD stage 4 and 5 patients?
 - Goals of Care
 - Advance Care Planning
3. Are the following interventions* effective and safe for the following symptoms/signs in CKD stage 4 and 5 patients for non-dialysis care?
 - fatigue/lethargy
 - uraemic pruritus
 - sleep disturbances
 - pain
 - gastrointestinal symptoms
 - dyspnoea
 - psychological/mood disturbance
 - neurological symptoms
 - Restless Leg Syndrome
 - end of life care including preferred place of death

*non-physical/pharmacological/psychosocial/dietary and fluid intervention
4. How should CKD stage 4 and 5 patients on non-dialysis care be followed-up?
 - Hospital
 - Clinic
 - Community palliative care

Appendix 3a

ADVANCE CARE PLANNING FOR CHRONIC KIDNEY DISEASE PATIENTS Appendix 3a

Shared decision-making between healthcare professionals, patients and their families

This form serves as communication tool and should be filled and signed by nephrologists or, if not available, general internal medicine physicians or family medicine specialists. If the patient is co-managed at other healthcare institutions, a copy of this form should be attached to the referral letter and the patient's follow-up card or books.

The following groups of patients should undergo advance care planning (ACP):

1. Chronic Kidney Disease Stage 5
2. Upon commencing kidney replacement therapy
3. Annually for patients on maintenance dialysis
4. When patients deteriorate while on maintenance dialysis (e.g. hospital admissions or development of complications) or opt for dialysis withdrawal

Name:	Date:
IC:	

A OPTION OF RENAL REPLACEMENT THERAPY

Tick one

This decision should be made through shared decision-making between patients, families and nephrologists, or if unavailable, family medicine specialists or internal medicine physicians.

- Haemodialysis
- Peritoneal dialysis
- Non-dialysis therapy/conservative kidney management
- Unsure of options, including delay in commencement of dialysis
- Patient is already in dialysis

B CARDIOPULMONARY RESUSCITATION (CPR):

Tick one

If patient has no pulse and is not breathing.

If patient is NOT in cardiopulmonary arrest, follow orders in Sections C and D.

- Attempt Resuscitation/CPR** (Selecting CPR in Section B **requires** selecting Dialysis and Full Treatment in Section C)
- Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

C MEDICAL INTERVENTIONS: If patient is found with a pulse and/or is breathing/very ill state:

- Dialysis** - the primary goal is to prolong life by all medically effective means
Patients agree to try dialysis if the patient present very ill as an emergency. Patient and family must be informed that in the event of emergency, if patient is clinically unstable, dialysis may be possible.

AND/OR

- Full Treatment** - the primary goal is to prolong life by all medically effective means
In addition to treatments described in Selective Treatment and Comfort-Focused Treatment, this includes emergency dialysis, use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated.

Trial Period of Full Treatment (withdraw if no improvement following time trial treatment) _____ (duration)

- Selective Treatment** - the goal is to treat medical conditions while avoiding burdensome measures
In addition to treatments described in Comfort-Focused Treatment, this includes use medical treatment, intravenous (IV) antibiotics and IV fluids as indicated, avoidance of intubation, may use non-invasive positive airway pressure and general avoidance of intensive care.

- Comfort-focused Treatment** - the primary goal is to maximise comfort (without dialysis)
Relieve pain and suffering with medication by any route as needed, use oxygen, suctioning and manual treatment of airway obstruction, avoidance of treatments listed in Full and Selective Treatment unless consistent with the comfort goal.

Additional Orders (this may include goals of care and care preferences):

D ARTIFICIALLY ADMINISTERED NUTRITION:

Offer food by mouth if feasible and desired.

- Long-term artificial nutrition, including feeding tubes. Additional Orders: _____
 Trial period of artificial nutrition, including feeding tubes.
 No artificial means of nutrition, including feeding tubes.

E INFORMATION AND SIGNATURE:

Discussed with: Patient (Patient Has Capacity) Next of kin

Signature of Nephrologist/Internal Medicine Physician/Family Medicine Specialist:

My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

Name of Nephrologist: _____ MMC no: _____

Nephrologist's Signature: (required) _____ Date: _____

Signature of Patient

I am aware that this form is voluntary. By signing this form, this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name: _____

Signature: (required) _____ Date: _____

Signature of Next of Kin

I am aware that this form is voluntary. By signing this form, the next of kin acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name: _____

Relationship: (write self if patient) _____

Signature: (required) _____ Date: _____

ACP promotes good communication. It is not legally binding and management will need clinical judgement and discussions with family during acute clinical presentation.

Adapted: Center for Ethics in Health Care and National POLST Paradigm Program,
(Available at: <https://polst.org/form-patients/>).

BORANG PERANCANGAN AWAL PESAKIT KRONIK KEGAGALAN BUAH PINGGANG

Perancangan rawatan perlu dibuat bersama antara profesional penjagaan kesihatan, pesakit dan keluarga mereka. Borang ini bertujuan untuk komunikasi, perlu diisi dan ditandatangani oleh pakar nefrologi; jika tidak ada - pakar perubatan dalam am/pakar perubatan keluarga. Jika pesakit diuruskan bersama di institusi penjagaan kesihatan lain, salinan borang ini perlu dilampirkan bersama surat rujukan dan kad atau buku susulan pesakit.

Kumpulan pesakit ini harus menjalani Perancangan Awal:

1. Penyakit Buah Pinggang Kronik Tahap 5
2. Sebaik sahaja mereka memulakan rawatan dialisis
3. Setiap tahun jika pesakit dialisis seumur hidup
4. Apabila kesihatan pesakit dialisis merosot (contoh termasuk ke hospital, komplikasi) dan mereka yang memilih untuk tidak menjalani / memberhentikan dialisis

Nama:
IC:

Tarikh:

A RAWATAN PILIHAN PENYAKIT KRONIK BUAH PINGGANG TAHAP 5

Tanda
satu

Ini adalah keputusan bersama yang dibuat antara pesakit, keluarga dan Pakar Nefrologi dan jika tiada, Pakar Perubatan Keluarga atau Pakar Perubatan Dalamam.

- Hemodialisis
- Dialisis Peritoneal
- Rawatan tanpa dialisis / rawatan komprehensif konservatif
- Tidak pasti; termasuk ingin memulakan dialisis bila sudah bergejala / tenat
- Pesakit sedang menjalani rawatan dialisis seumur hidup

B RESUSITASI KARDIOPULMONARI (CPR):

Tanda
satu

Jika pesakit tidak mempunyai denyut nadi dan tidak bernafas

Jika pesakit masih ada nadi dan tidak memerlukan resusitasi (CPR), sila ke Seksyen C dan D.

- Percubaan Resusitasi/CPR (Memilih CPR dalam Seksyen C memerlukan pemilihan Dialisis dan kesemua rawatan Seksyen C)
- Tiada Percubaan Resusitasi/Do Not Attempt Resuscitation/DNR (Kematian semulajadi)

C INTERVENSI PERUBATAN: Jika pesakit didapati tiada nadi dan/atau sedang bernafas/ dalam keadaan sangat tenat.

- Dialisis - matlamat utama adalah untuk memanjangkan hayat dengan kaedah perubatan yang berkesan. Pesakit bersetuju untuk mencuba rawatan dialisis secara kecemasan jika sudah sakit tenat. Pesakit dan keluarga mesti diterangkan bahawa sekiranya berlaku kecemasan jika keadaan pesakit tidak stabil, dialisis mungkin tidak boleh ditawarkan.

DAN/ATAU

- Rawatan Penuh – matlamat utama untuk memanjangkan hayat dengan semua cara rawatan yang telah dibuktikan berkesan. Tambah kepada rawatan yang diterangkan, rawatan selektif dan fokus penyelesaian, bersetuju untuk dialisis kecemasan, intubasi.
 - Tempoh Percubaan Rawatan Penuh (berhenti rawatan jika tiada peningkatan selepas percubaan rawatan *time trial treatment*), _____ (tempoh masa)

- Rawatan Selektif – matlamat rawatan adalah untuk mengelakkan rawatan yang membebankan. Selain rawatan yang diterangkan dalam rawatan berfokus kepada penyelesaian, rawatan yang ditawarkan termasuk antibiotik intravena, dan cecair intravena jika perlu. Jangan lakukan intubasi. Boleh menggunakan sokongan pernafasan yang bukan invasif. Elak rawatan di unit rawatan rapi.
- Rawatan Fokus Keselesaan – matlamat utama adalah untuk memaksimumkan keselesaan (tanpa dialisis)

Melegakan kesakitan dan penderitaan dengan ubat melalui apa-apa cara yang diperlukan; penggunaan oksigen, penyedutan (suction), dan rawatan manual membantu saluran pernafasan. Tidak menggunakan rawatan yang disenaraikan di bawah Rawatan Penuh dan Selektif kecuali selaras dengan matlamat keselesaan.

Arahan tambahan (boleh merangkumi matlamat penjagaan, keutamaan penjagaan):

D PEMBERIAN PEMAKANAN SECARA MELALUI TIUB:

Tawarkan makanan melalui mulut jika boleh dan diingini.

- Pemakanan buatan jangka panjang. Tambahan: _____
 Tempoh percubaan pemakanan buatan _____
 Tiada pemakanan melalui tiub. _____

E MAKLUMAT DAN TANDATANGAN:

Perbincangan bersama: Pesakit (Pesakit mempunyai keupayaan membuat keputusan) Waris

Tandatangan Pakar Nefrologi/Doktor Perubatan/Pakar Perubatan Keluarga:

Tandatangan saya di bawah mengesahkan, setakat pengetahuan saya, bahawa arahan ini adalah selaras dengan keadaan perubatan dan keutamaan pesakit.

Nama Pakar Nefrologi/wakil: _____ No MPM: _____

Tandatangan: (diperlukan)

Tarikh:

Tandatangan Pesakit:

Saya sedar bahawa borang ini adalah secara sukarela. Dengan menandatangani borang ini, permintaan ini berkaitan dengan langkah resusitasi adalah selaras dengan kehendak yang diketahui dan demi kepentingan terbaik individu yang menjadi subjek borang ini.

Nama penuh:

Tandatangan: (diperlukan)

Tarikh:

Tandatangan Waris:

Saya sedar bahawa borang ini adalah secara sukarela. Dengan menandatangani borang ini, waris terdekat mengakui bahawa permintaan ini berkaitan dengan langkah resusitasi adalah selaras dengan kehendak yang diketahui dan demi kepentingan terbaik individu yang menjadi subjek borang ini.

Nama penuh:

Hubungan dengan pesakit:

Tandatangan: (diperlukan)

Tarikh:

Perancangan awal menggalakkan komunikasi yang baik, tidak terikat dari segi undang-undang dan rawatan masih memerlukan pertimbangan klinikal serta perbincangan dengan keluarga di semua situasi klinikal.

Adapted: Center for Ethics in Health Care and National POLST Paradigm Program,
(Available at: <https://polst.org/form-patients/>).

Appendix 4

SUGGESTED MEDICATION DOSAGES AND ADVERSE EFFECTS

Drug	Recommended Dosages	Adverse Events (AEs)	Remarks
Erythropoietin-stimulating agents			
Epoetin alfa and beta	CKD not receiving dialysis: 20 - 50 u/kg every 1 - 2 weeks	Hypertension, headache, pruritus, nausea, vomiting, arthralgia, fever, abdominal pain, diarrhoea, nasopharyngitis	CKD not receiving dialysis: Increase or decrease dose and/or dosing frequency as needed (generally not given more than once per week)
Darbepoetin	CKD not receiving dialysis: 0.45 mcg/kg once every 2 - 4 weeks		
Methyl glycol-epoetin beta	CKD not receiving dialysis: 1.2 mcg/kg monthly or 0.6 mcg/kg every 2 weeks		
Iron-containing preparations			
Ferrous fumarate	Elemental iron of 200 mg/day in up to 3 divided doses	GI AEs (constipation, diarrhoea, nausea and vomiting), dark green stools	Elemental iron content available in ferrous fumarate: 33% (200 mg ferrous fumarate = 66 mg elemental iron) Administered between meals as intestinal absorption may be impaired by food and antacids. Elemental iron concentration: 50 mg/mL
Iron dextran 50 mg Fe/mL Injection (Low molecular weight)	20 mg/kg as maximum single dose Administer a 25 mg test dose initially. If tolerated, proceed with the remaining dose	Bradycardia, changes in blood pressure, abdominal pain, injection site reactions (inflammation), pruritus, headache, muscle cramps, nasopharyngitis	Elemental iron concentration: 20 mg/mL People with CKD G1-G5 not receiving HD require multiple patients' visits as 1000 mg cannot be given at a single dose
Iron (III) hydroxide sucrose complex 20 mg/mL solution for injection	Do not exceed 200 mg as a single dose		
Antihistamines			
Chlorpheniramine	eGFR \leq 30 mL/min/1.73m ² : no initial dosage adjustment necessary, 4 mg every 4 - 6 hours, maximum dose: 24 mg/day	Drowsiness	Use with caution as half-life is greatly prolonged in patients with advanced CKD

Drug	Recommended Dosages	Adverse Events (AEs)	Remarks
Lorazepam	eGFR \leq 30 mL/min/1.73m ² : 10 mg every 48 hours	Headache, dyspepsia, flu-like symptoms	Use with caution in patients with renal impairment
Gabapentinoids			
Gabapentin	CrCl <15 mL/min: Starting dose 100 mg on alternate nights; maximum dose: 300 mg at bedtime	Dizziness, drowsiness, status epilepticus, tremor	Use with caution in patients with moderate to severe renal impairment
Pregabalin	CrCl <15 mL/min: 50 - 75 mg/day	Dizziness, drowsiness, peripheral oedema, suicidal ideation, weight gain	Use with caution in patients with moderate to severe renal impairment
Benzodiazepines			
Diazepam	Seizure: IV: 5 - 10 mg as a single dose Rectal: 10 - 20 mg as a single dose Oral (sublingual): 0.5 - 1 mg	Drowsiness, vasodilation, diarrhoea	No renal dosage adjustment necessary; use with caution, especially with prolonged course
Lorazepam	Seizure: SC: 5 mg stat CSCI: 20 - 30 mg (increase by 5 - 10 mg every 24 hours)	Drowsiness, hypotension	
Midazolam		Drowsiness, nausea, vomiting, erythema and pain at injection site	
Zolpidem	Insomnia: Oral: 5 mg (max dose: 10 mg/day)	Drowsiness, dizziness, hallucination	No renal dosage adjustment necessary
Opioids			
Fentanyl	Equianalgesic dose of total 24 hours opioid requirement		Transdermal fentanyl can only be used when opioid requirements are stable and never in an opioid-naïve patient
Morphine	Start with IR morphine in low doses and increase dose intervals (1 - 2 mg every 6 hours instead of every 4 hours)	Drowsiness, dizziness, nausea, vomiting, constipation	Accumulation of active metabolites of morphine in kidney can cause opioid toxicity Avoid using sustained-release formulation
Oxycodone	Start with IR oxycodone in low doses and increase dose intervals (1 - 2 mg every 6 hours instead of 4 hours)		Avoid using sustained-release formulation

Drug	Recommended Dosages	Adverse Events (AEs)	Remarks
Antiemetics			
Ondansetron	Oral/IV: 4 - 8 mg as a single dose; may repeat 4 - 8 mg every 4 - 8 hours as needed	Constipation, headache, urticaria, prolonged QT interval, bradycardia	No renal dosage adjustment necessary
Metoclopramide	Oral/IV/SC: Initial: 5 - 10 mg every 4 to 6 hours; if insufficient relief with intermittent dosing, may switch to IV or SC continuous infusion	Drowsiness, fatigue, extrapyramidal symptoms, hyperprolactinaemia	Use with caution in patients with moderate to severe renal impairment.
Haloperidol	CrCl ≤10 mL/min: Administer ~33% (or less) of usual total daily dose IV/SC: Oral: 0.75 - 1 mg every 6 - 8 hours	Angioedema, extrapyramidal symptoms, drowsiness	No renal dosage adjustment necessary
Olanzapine	Oral: 5 mg OD (max dose: 20 mg/day)		
Laxatives			
Lactulose	15 - 30 mL daily; may increase up to 60 mL daily if necessary	Abdominal distension, bloating, nausea, vomiting, flatulence	
Polyethylene glycol 4000	10 - 20 g (1 - 2 sachet)/day	Abdominal pain, diarrhoea	
Bisacodyl	Oral: 5 - 15 mg OD Rectal (suppository): 10 mg OD	Abdominal pain, diarrhoea, flatulence, ischaemic colitis	
Glycerin enema	Rectal: One adult suppository OD as needed	Abdominal cramps, rectal irritation, tenesmus	No renal dosage adjustment necessary
Antidepressants			
Sertraline	Oral: Initial dose: 25 mg once daily. Dose may be increased in 25 mg increments once weekly based on response and tolerability, up to a maximum of 200 mg/day.	Diarrhoea, nausea, xerostomia, dizziness, insomnia	No renal dosage adjustment necessary

Drug	Recommended Dosages	Adverse Events (AEs)	Remarks
Duloxetine	Oral: 30 mg OD; titrate slowly based on response, not to exceed 60 mg OD	Weight loss, abdominal pain, decreased appetite, nausea, vomiting, xerostomia, drowsiness	Use with caution in patients with CrCl <30 mL/min.

References:

1. Wilcock A, Howard P, Charlesworth S. Palliative Care Formulary 7th ed. United Kingdom: Pharmaceutical Press, 2020.
2. UpToDate, Connor RF (Ed), Wolters Kluwer. (Accessed on March 8, 2025)
3. Ministry of Health Malaysia. CPG Management of Cancer Pain (Second Edition). Putrajaya: MOH; 2023.
4. Scottish Palliative Care Guideline Medicines information | Right Decisions (Available at: <https://rightdecisions.scot.nhs.uk/scottish-palliative-care-guidelines/medicines-information/>)

ENERGY CONSERVATION STRATEGIES

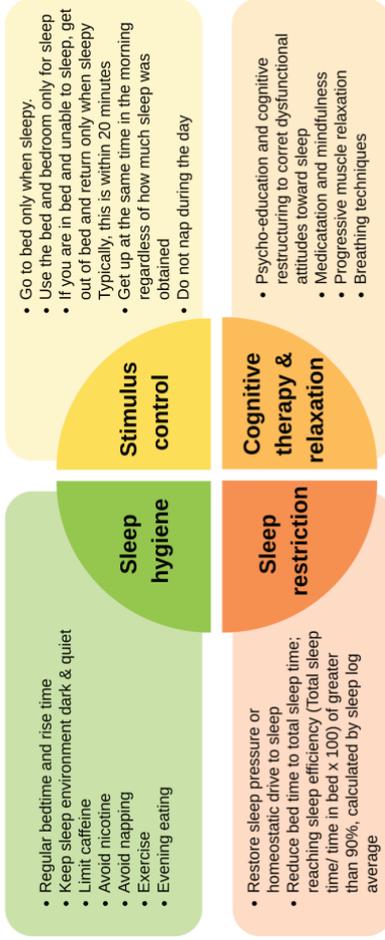
Energy conservation strategies	Description
1. Organising daily routine and activities	<p>It includes planning and prioritising the day around, completing the most important tasks first, as well as the importance of not over-panning the day. This strategy includes activities such as:</p> <ol style="list-style-type: none"> Plan a daily activity schedule that alternates light and heavy tasks. Avoid unnecessary steps of a task. Prioritise the work. Analyse the work to be done. Breaks the tasks into stages. Gather and arrange supplies or tools for daily activities before starting.
2. Use energy-efficient appliances and the right equipment	<p>Energy can be conserved by using energy-efficient appliances and the right equipment.</p> <ol style="list-style-type: none"> Use lightweight, appropriate equipment for the task. If available, use modern household utensils or electric appliances to save energy, such as non-stick kitchenware, electric can openers and micro-ovens. Use assistive devices such as long handled reacher to minimise the need to stoop or bend over when retrieving objects from the floor.
3. Work with proper pacing and avoid rushing	<p>Proper pacing is required to conserve energy when it is available. Rushing through the task when the energy level is low will exacerbate the fatigue.</p> <ol style="list-style-type: none"> Allow ample time to finish an activity. Keep a slow and steady pace, and do not rush. Rest before the exhaustion. Have sufficient rest after completing a task and moving on to the next one.
4. The value of rest and incorporating rest periods throughout the day	<p>Rest is important. Increasing rest breaks will increase the overall endurance and give the body time to recover.</p> <ol style="list-style-type: none"> Frequent short rests are of more benefit than fewer longer ones, whether at home or work. Balance activities with rest and learn to allow time for rest when planning a day's activities. Pre-schedule the rest time. Rest means doing nothing at all. The amount of rest that is needed is based on the amount of activity in each day. Listening to music or using relaxation tapes may help you to relax. If possible, lie down to rest.
5. Delegating tasks	<p>Delegating the task to someone else wherever possible helps to save the energy for things that is more essential.</p> <ol style="list-style-type: none"> Do not try to do a two-man job by one. Ask for help with tiring activities. Tell family or friends if you need help with tasks that are difficult.

Energy conservation strategies	Description
6. Using proper body mechanics and posture	<p>Using proper body mechanics and posture is important to avoid unnecessary stress on muscles and joints, which in turn can create unwanted fatigue.</p> <ol style="list-style-type: none"> a. Sit down for activities whenever possible. b. Keep a stool handy to allow you to sit down to perform tasks. c. Avoid tasks that require prolonged standing, squatting, or stooping. d. Use the strongest muscle groups during the activity. e. Push or pull and use wheels under object whenever possible. f. When lifting, bend the knees and place a chair by the sides to help if necessary. g. When lifting, keep object close to the body. h. Keep your body straight while performing a task. Poor posture consumes more energy. i. Keep the arm straight and close to the body while carrying the object and spread the load between both arms at the same time. j. Support the elbows on a table or firm surface while performing a task to avoid positions that make you tired. E.g. During shaving, peeling potatoes skin. k. When sitting down to rest, lean the body forward slightly. Relax the shoulders while keeping hands on both thighs and rest the feet comfortably on the floor. l. Raising arms too high for a prolonged period at work is energy-consuming. Avoid this posture by lowering the height of the working table to an appropriate level. m. Avoid bending over while retrieving objects from the floor. Before lifting, try keeping the body straight by bending the hips and knees and then straightening the legs to assist in lifting the object. n. Keep the heavy object close to the body while lifting and carrying. o. When Climbing <ul style="list-style-type: none"> - Walks on the whole foot. - Use handrail for support - Pause at least 1 second between each step
7. Simplifying tasks	<p>The principle of task simplification includes sitting to work as much as possible and eliminating the steps or jobs that are unnecessary to conserve energy.</p> <ol style="list-style-type: none"> a. Cancel tasks that are not necessary. b. Simplify the methods of works. c. Sit to work whenever possible. d. Adjust the height of work surfaces to allow for good posture. e. Use equipment when necessary to conserve the energy.

Source: Sharma S, Alexander KE, Green T, et al. Energy conservation education intervention for people with end-stage kidney disease receiving haemodialysis (EVEREST): A two-arm parallel group study. *Int J Nurs Stud.* 2025;166:105032.

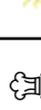
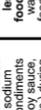
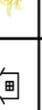
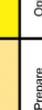
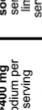
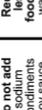
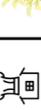
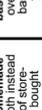
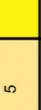
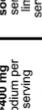
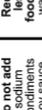
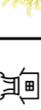
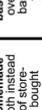
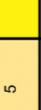
Appendix 6

COMPONENTS OF COGNITIVE BEHAVIOURAL THERAPY FOR INSOMNIA (CBT-I)¹



Adapted: Gopal A, Farragher J, Jassal SV, Mucsi I. Sleep Disorders in CKD: A Review. Am J Kidney Dis. Published online February 28, 2025.

TIPS TO REDUCE SODIUM / NATRIUM INTAKE

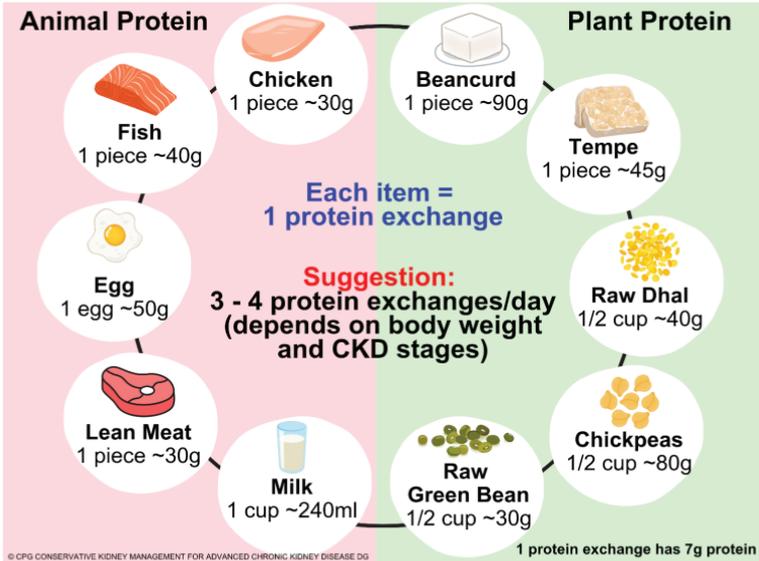
Tips	1	2	3	4	5	6	7
Home cooking	Use fresh ingredients and limit ultra-processed food 	Enhance flavour with fresh aromatics (citrus, shallot, oil, vinegar) or natural umami (tomato, mushroom) 	Enjoy food with less or without sodium condiments 	If needed, add sodium condiments only after the food has cooled 	Prepares homemade broth instead of store-bought 	Opt for fibre-based or wheat-based (e.g. noodles) 	Opt for simple or one-pot complete meals 
Eating Out	Choose menu with least processed ingredients 	Choose menu with clear broth or limited soup volume intake 	Swap fried rice (chicken, beef, pork, etc.) for plain rice 	Ask for seafood, gravies, sauce or dressing (mayo, etc.) dip instead of pour 	Do not add condiments (soy sauce, etc.) during eating 	Request for food and alert waiter if the food served is salty 	Practice portion control eating 
Groceries	Choose unsalted spreads (butter, margarine, etc.) 	Keep healthy snacks on hand (vegetable sticks, fresh fruits) 	Choose lower sodium brand when possible 	Read sodium or sodium nutrition information (food labels) 	Avoid foods >400 mg sodium per serving 	Limit snack of <200 mg sodium per serving and limit to 1-2 servings/day 	Watch out for sodium additives listed as stabilisers, emulsifiers, etc. (not just salt (sodium chloride)) 
<p>Recommendation for daily sodium / natrium intake: <2000 mg per day</p>							

© CFG CONSERVATIVE KIDNEY MANAGEMENT FOR ADVANCED CHRONIC KIDNEY DISEASE DG

- Ultra-processed foods:¹
 - o industrially produced products primarily composed of extracted food substances, derivatives like hydrogenated fats, and synthesised additives.
 - o include sugary drinks, snacks, confectionery, packaged baked goods, instant noodles and soups, processed meats, baby food products, and ready-to-eat meals.

Reference: Monteiro, C.A., Cannon, G., Levy, R., et al. 2016. NOVA. The star shines bright. World Nutrition, 7(1-3), pp.28-38.

DIETARY PROTEIN INTAKE RECOMMENDATION



Appendix 9a

IPOS-RENAL STAFF VERSION (ONE WEEK)

Patient's name :
 Patient number :
 Date (dd/mm/yyyy) :

Q1. What have been the patient's main problems or concerns over the past week?

1.
2.
3.

Q2. Please tick the box that describes how the patient has been affected by each of the following symptoms, over the past week?

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot assess (e.g. unconscious)
Pain	<input type="checkbox"/>					
Shortness of breath	<input type="checkbox"/>					
Weakness or lack of energy	<input type="checkbox"/>					
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>					
Vomiting (being sick)	<input type="checkbox"/>					
Poor appetite	<input type="checkbox"/>					
Constipation	<input type="checkbox"/>					
Sore or dry mouth	<input type="checkbox"/>					
Drowsiness	<input type="checkbox"/>					
Poor mobility	<input type="checkbox"/>					
Itching	<input type="checkbox"/>					
Difficulty Sleeping	<input type="checkbox"/>					
Restless legs or difficulty keeping legs still	<input type="checkbox"/>					
Changes in skin	<input type="checkbox"/>					
Diarrhoea	<input type="checkbox"/>					

Please list any other symptoms and tick the box to show how you feel each of these symptoms has affected the patient over the past week.

1. _____
2. _____
3. _____

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess (e.g. unconscious)
Q3. Have s/he been feeling anxious or worries about his/her illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Q4. Have any of his/her family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Q5. Do you think s/he feel depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all	Cannot assess (e.g. unconscious)
Q6. Do you think s/he has felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Q8. Has the patient had as much information s/he wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
	Problems addressed/ No Problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed	Cannot assess (e.g. unconscious)
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
	None at all		Up to half a day wasted		More than half a day wasted	
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests?	0 <input type="checkbox"/>		1 <input type="checkbox"/>		2 <input type="checkbox"/>	

Adopted from: Palliative care Outcome Scale (POS) - IPOS-Renal and Translations.
(Available at: <https://pos-pal.org/maix/i-pos-renal.php>)

Appendix 9b

IPOS-RENAL PATIENT VERSION (ONE WEEK)

Patient's name :

Patient number :

Date (dd/mm/yyyy) :(for staff's use)

Q1. What have been your main problems or concerns over the past week?

4.
5.
6.

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past week?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	<input type="checkbox"/>				
Shortness of breath	<input type="checkbox"/>				
Weakness or lack of energy	<input type="checkbox"/>				
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>				
Vomiting (being sick)	<input type="checkbox"/>				
Poor appetite	<input type="checkbox"/>				
Constipation	<input type="checkbox"/>				
Sore or dry mouth	<input type="checkbox"/>				
Drowsiness	<input type="checkbox"/>				
Poor mobility	<input type="checkbox"/>				
Itching	<input type="checkbox"/>				
Difficulty Sleeping	<input type="checkbox"/>				
Restless legs or difficulty keeping legs still	<input type="checkbox"/>				
Changes in skin	<input type="checkbox"/>				
Diarrhoea	<input type="checkbox"/>				

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1. _____
2. _____
4. _____

Over the past week:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worries about your illness or treatment?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q5. Have you been feeling depressed?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
Q8. Have you had as much information as you wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	Problems addressed/ No Problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
	None at all	Up to half a day wasted	More than half a day wasted		
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>		
	On my own	With help from a friend or relative	With help from a member of staff		
Q11. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

If you are worried about any of the issues raised on this questionnaire, then please speak to your doctor or nurse

Adopted from: Palliative care Outcome Scale (POS) - IPOS-Renal and Translations.
(Available at: <https://pos-pal.org/maix/i-pos-renal.php>)

Appendix 9c

IPOS-RENAL STAFF VERSION (3 DAYS)

Patient's name :
 Patient number :
 Date (dd/mm/yyyy) :

Q1. What have been the patient's main problems or concerns over the past 3 days?

7.
 8.
 9.

Q2. Please tick the box that describes how the patient has been affected by each of the following symptoms, over the past 3 days?

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot assess (e.g. unconscious)
Pain	<input type="checkbox"/>					
Shortness of breath	<input type="checkbox"/>					
Weakness or lack of energy	<input type="checkbox"/>					
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>					
Vomiting (being sick)	<input type="checkbox"/>					
Poor appetite	<input type="checkbox"/>					
Constipation	<input type="checkbox"/>					
Sore or dry mouth	<input type="checkbox"/>					
Drowsiness	<input type="checkbox"/>					
Poor mobility	<input type="checkbox"/>					
Itching	<input type="checkbox"/>					
Difficulty Sleeping	<input type="checkbox"/>					
Restless legs or difficulty keeping legs still	<input type="checkbox"/>					
Changes in skin	<input type="checkbox"/>					
Diarrhoea	<input type="checkbox"/>					

Please list any other symptoms and tick the box to show how you feel each of these symptoms has affected the patient over the past 3 days.

1. _____
2. _____
5. _____

Over the past 3 days:

	Not at all	Occasionally	Sometimes	Most of the time	Always	Cannot assess (e.g. unconscious)
Q3. Have s/he been feeling anxious or worries about his/her illness or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q4. Have any of his/her family or friends been anxious or worried about you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5. Do you think s/he feel depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all	Cannot assess (e.g. unconscious)
Q6. Do you think s/he has felt at peace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q8. Has the patient had as much information s/he wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Problems addressed/ No Problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed	Cannot assess (e.g. unconscious)
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	None at all		Up to half a day wasted		More than half a day wasted	
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests?	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>	

Adopted from: Palliative care Outcome Scale (POS) – IPOS-Renal and Translations.
(Available at: <https://pos-pal.org/maix/ipos-renal.php>)

Appendix 9d

IPOS-RENAL PATIENT VERSION (3 DAYS)

Patient's name :
 Patient number :
 Date (dd/mm/yyyy) : (for staff's use)

Q1. What have been your main problems or concerns over the past 3 days?

10.
 11.
 12.

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick the box that best describes how it has affected you over the past 3 days?

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	<input type="checkbox"/>				
Shortness of breath	<input type="checkbox"/>				
Weakness or lack of energy	<input type="checkbox"/>				
Nausea (feeling like you are going to be sick)	<input type="checkbox"/>				
Vomiting (being sick)	<input type="checkbox"/>				
Poor appetite	<input type="checkbox"/>				
Constipation	<input type="checkbox"/>				
Sore or dry mouth	<input type="checkbox"/>				
Drowsiness	<input type="checkbox"/>				
Poor mobility	<input type="checkbox"/>				
Itching	<input type="checkbox"/>				
Difficulty Sleeping	<input type="checkbox"/>				
Restless legs or difficulty keeping legs still	<input type="checkbox"/>				
Changes in skin	<input type="checkbox"/>				
Diarrhoea	<input type="checkbox"/>				

Please list any other symptoms not mentioned above, and tick the box to show how they have affected you over the past week?

1. _____	<input type="checkbox"/>				
2. _____	<input type="checkbox"/>				
6. _____	<input type="checkbox"/>				

Over the 3 days:

	Not at all	Occasionally	Sometimes	Most of the time	Always
Q3. Have you been feeling anxious or worries about your illness or treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q4. Have any of your family or friends been anxious or worried about you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5. Have you been feeling depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Always	Most of the time	Sometimes	Occasionally	Not at all
Q6. Have you felt at peace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q8. Have you had as much information as you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Problems addressed/ No Problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	None at all	Up to half a day wasted	More than half a day wasted		
Q10. How much time do you feel has been wasted on appointments relating to your healthcare, e.g. waiting around for transport or repeating tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
	On my own	With help from a friend or relative	With help from a member of staff		
Q11. How did you complete this questionnaire?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

If you are worried about any of the issues raised on this questionnaire, then please speak to your doctor or nurse

Adopted from: Palliative care Outcome Scale (POS) - IPOS-Renal and Translations.
(Available at: <https://pos-pal.org/maix/ipos-renal.php>)

CAREGIVER TRAINING IN ADVANCED CHRONIC KIDNEY DISEASE

BASIC CARE & HYGIENE

-  **Oral Care**
Brush teeth 2x per day
Rinse after meals
-  **Skin Care**
Moisturise
Regular reposition to prevent pressure sores
-  **Perineal Care**
Keep area clean & dry to prevent infection
-  **Catheter Care**
Wash hands before & after handling
Do not pull or twist

FEEDING & NUTRITION

-  **Nutrition Basics**
Small frequent meals
Follow renal diet advice
Avoid unnecessary supplements
-  **Safe Oral Feeding**
Sit patient upright
Ensure swallowing
-  **NG/PEG Feeding**
Check tube placement before feeds
Flush with adequate water
Check feeding tolerance

PHYSIOTHERAPY & MOBILITY

-  **Transferring**
Use correct body mechanics
Avoid lifting alone
Use transfer aids
-  **Exercise**
Gentle range-of-motion exercises to maintain mobility

PHYSIOTHERAPY & MOBILITY

-  **ADL Training**
Encourage independence in dressing, grooming & toileting where possible
-  **Fall Prevention**
Clear clutter
Use non slip footwear
Ensure good lighting
Assist when walking if unsteady

Source: AI-generated image using ChatGPT (GPT-5, Open AI, August 2025)

RESOURCES FOR CAREGIVERS OF PERSONS WITH ADVANCED CHRONIC KIDNEY DISEASE

Caregivers' Needs	Example of Resources
Personal coping strategies	<ul style="list-style-type: none"> • Active coping and reframing strategies • Adjusting paid work arrangements to fit more easily with caregiving • Being assertive in asking for support • Checking out formal support options • Having a religious practice or spiritual philosophy • Looking after own physical, psychological and spiritual health
Support from family/friends	<ul style="list-style-type: none"> • Practical assistance and emotional support from extended family and the community
Support from healthcare professionals	<ul style="list-style-type: none"> • Caregiver support groups* • Good quality respite care • Good quality and readily available information (e.g. knowledge of service, information about recipient's illness and prognosis)* • Respectful relationships with formal services based on good communication
Support from community/ government/ agencies	<ul style="list-style-type: none"> • Create new and solidify policies to enhance caregiving as a formal and informal service. This includes: <ul style="list-style-type: none"> ○ Acknowledging the role of formal and informal caregivers using age and gender lenses ○ Enabling informal caregivers to reconcile caregiving with their employment and personal lives ○ Providing informal caregivers and community support groups with adequate financial assistance or tax relief and/or social securities ○ Improving access to community-based services* ○ Improving and enhancing access to information and training ○ Protecting health and wellbeing of informal caregivers • Improve coordination between agencies and provider organisations • Reduce stigma and discrimination towards the recipients of care and their caregivers

*Links to local and international resources for caregivers:

Malaysian resources:

1. MyGovernment Digital Services (resources)
<https://www.malaysia.gov.my/portal/category/1539>
2. Hospis Malaysia Carer Guide Book
<https://www.hospismalaysia.org/resources/>
3. Malaysian Hospice and Palliative Care Council Compilation of Carer Resources
<https://www.malaysianhospicecouncil.com/>
4. Palliative Care Unit Hospital UiTM YouTube Channel
<https://www.youtube.com/@palcareuitm4720/playlists>
5. Malaysian Association of Paediatrics Palliative Care
<https://www.mappac.org/>

International resources:

1. Betterhealth, Victoria, Australia
<https://www.betterhealth.vic.gov.au/servicesandsupport/carers-caring-and-respite-care-services>
2. CarerHelp, Australia
<https://www.carerhelp.com.au/>

LIST OF ABBREVIATIONS

ACP	Advance Care Planning
AEs	adverse effect(s)
BP	blood pressure
CAH	clinical assisted-hydration
CBT	cognitive-behavioural therapy
CKM	conservative kidney management
CKD	chronic kidney disease
CPG	clinical practice guidelines
CrCl	creatinine clearance
CSCI	continuous subcutaneous infusion
DBP	diastolic blood pressure
DG	development group
dL	decilitre
eGFR	estimated glomerular filtration rate
ESA	erythropoiesis-stimulating agents
ESAS-r	Edmonton Symptom Assessment System Revised
ESKD	End-stage kidney disease
ESPEN	European Society for Clinical Nutrition and Metabolism
Fe	ferum
g	gramme
GABA	gamma-aminobutyric acid
GI	gastrointestinal
GRADE	Grading Recommendations, Assessment, Development and Evaluation
Hb	haemoglobin
HbA1C	haemoglobin A1C
HD	haemodialysis
HIF-PHI	hypoxia-inducible factor prolyl hydroxylase inhibitors
HRQoL	health-related quality of life
IR	immediate-release
IPOS	Integrated Palliative Outcome Scale
IV	intravenous
kcal	kilocalories
KDIGO	Kidney Disease: Improving Global Outcomes
KDOQI	The National Kidney Foundation's Kidney Disease Outcomes Quality Initiative
kg	kilogramme
KRT	kidney replacement therapy
KSC	kidney supportive care
KFRE	Kidney Failure Risk Equation
L	litre
LC n-3 PUFA	long chain omega-3 polysaturated fatty acids
mg	milligramme
min	minute
mL	millilitre
mmol	millimol
MoH	Ministry of Health
µg	microgramme
NGO	non-government organisation
NICE	The National Institute for Health and Care Excellence
NS	non-significant

NSAIDs	non-steroidal anti-inflammatory drugs
OD	once daily
PD	peritoneal dialysis
PEW	protein-energy-wasting
QoL	quality of life
RLS	restless leg syndrome
SBP	systolic blood pressure
SDM	shared decision-making
NSAIDs	non-steroidal anti-inflammatory drugs
SMD	standard mean difference
TSAT	transferrin saturation
u	unit
VAS	Visual Analogue Scale
WHO	World Health Organization

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