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Calciphylaxis – Practical, Person-Centred Care Guide for UK Clinicians

Focus: delivering the diagnosis sensitively, holistic MDT care, prioritising wound care and pain control, and maximising quality of life (QoL) alongside disease-directed therapy.

Evidence base: ERA CKD-MBD Working Group comprehensive review, Ten tips on how to deal with calciphylaxis patients, and CALCI-E lived experiences qualitative study.[1-3]

1. Diagnosing calciphylaxis

Diagnosis can be complex. The recent ERA CKD-MBD working group paper can help guide on when a biopsy, or imaging, may be appropriate: Calciphylaxis diagnosis, management and future directions: a comprehensive update on behalf of the European Renal Association CKD-MBD Working Group - PubMed

2. Preparing to deliver the diagnosis

Calciphylaxis is rare and frightening for patients. The way the diagnosis is communicated often shapes trust, engagement, and coping.

Before the discussion

- Ensure privacy and adequate time
- Review key facts: stage, ulceration, infection risk, current pain plan
- Check who the patient would like present (family/carer/advocate)

During the discussion

- Use clear, compassionate language
- Acknowledge uncertainty honestly (no single proven cure) but also share that there are good news stories
- Emphasize the importance of the team approach and symptom control (discuss dermatology, wound care support, pain team, role of supportive care – this can be active supportive care including symptom management)
- Signpost to patient information. An patient education video is available at the following link (in the resources section): Calciphylaxis: treatment, symptoms, causes and diagnosis
- Offer to involve family if the patient wishes
- Arrange a second review to revisit questions

3. Early MDT set-up

Calciphylaxis management is multidisciplinary and should be coordinated early.

- Renal consultant
- Dermatology
- Tissue viability/wound specialist
- Pain team
- Palliative/supportive care (early involvement can support quality of life)
- Renal dietitian
- Renal pharmacist
- Primary care
- District nurses

4. Pain control should be a priority

- Pain is often severe and undertreated
- Patients have emphasised the importance of feeling listened to
- The pain is often disproportionate to the physical appearance of the skin
- Ensure the pain team are involved

5. Wound care is central

- Early tissue viability input
- Gentle, atraumatic dressings – regular checks and dressing changes and continuity important
- Protect the surrounding skin
- Pressure offloading
- Odor management strategies

How the diagnosis is communicated often shapes trust, engagement, and coping.

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6. Holistic care & quality of life focus

Calciphylaxis affects far more than skin.

Physical

- Fatigue management
- Nutritional assessment (protein-energy wasting common)
- Dialysis tolerance review
- Sleep disturbance management

Psychological

- Anxiety and fear are common
- Offer: renal psychology referral (if available), counselling, peer support, Macmillan support line (for complex chronic illness coping, it is not cancer-specific only)

7. Palliative & supportive care

Emphasise that involvement does not mean stopping active treatment.

It helps with:

- Complex pain
- Symptom burden
- Advance care planning
- Goal setting

Active treatment and comfort-focused care should coexist.

8. Treatment discussions – framing expectations

Be honest:

- There is no guaranteed cure.

Treatments aim to:

- Improve wound healing
- Reduce progression
- Control pain
- Improve QoL

Discuss options clearly (explain all treatments –ensure patient feels involved):

- Optimising mineral balance
- Adjusting dialysis
- Stopping certain medications / trying new medications
- Explain benefits and uncertainties
- Revisit decisions regularly

9. Patient resources

- Kidney Care UK – www.kidneycareuk.org
- National Kidney Federation – www.kidney.org.uk
- Education video available - https://www.kidneyresearchuk.org

Practical checklist

At diagnosis

- ❑ Diagnosis explained compassionately
- ❑ Family involvement offered
- ❑ Pain escalated
- ❑ Tissue viability referral / district nurse involvement
- ❑ MDT notified/meetings
- ❑ Medications reviewed
- ❑ RaDaR / research involvement offered

Week 1–2

- ❑ Pain review
- ❑ Wound reassessment
- ❑ Nutritional review
- ❑ Psychological support offered
- ❑ Treatment plan documented

Ongoing

- ❑ QoL discussions
- ❑ Revisit goals of care
- ❑ Regular family updates (if desired)
- ❑ Clear community plan

Management should focus on:

- Relieving pain
- Supporting dignity
- Maximising quality of life
- Working transparently with patients and families
- Active treatment and comfort-focused care should coexist

References: 1. Huish S, Moore S, Alfieri C, Bellasi A, Cejka D, de Borst MH, Diaz-Tocados JM, Ferraro PM, Fusaro M, Haarhaus M, Hansen D, Kanbay M, Ketteler M, Sinha S. Calciphylaxis diagnosis, management and future directions: a comprehensive update on behalf of the European Renal Association CKD-MBD Working Group. Clin Kidney J. 2025;18(12):sfaf338. doi:10.1093/ckj/sfaf338. 2. Chewcharat A, Nigwekar SU. Ten tips on how to deal with calciphylaxis patients. Clin Kidney J. 2025;18(4):sfaf098. doi:10.1093/ckj/sfaf098. 3. Huish S, Bingham C, Treadgold BM, Sinha S. Lived experiences of patients with calciphylaxis (CALCI-E): a qualitative study. Journal of Nephrology. 2026;39(2):381–389. doi:10.1093/joneph/aajaf017.

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