

# Challenges of Medication Adherence in Slowly Progressing Diseases

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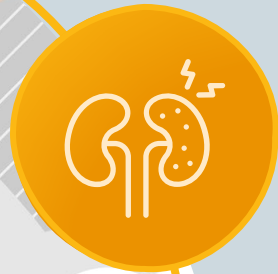
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# Renal disease demands lifelong treatment adherence



**Kidney disease can be asymptomatic but progressive, leading to kidney failure<sup>1,2</sup>**



**The burden of the disease and treatment is felt not only by the patients themselves, but also their caregivers and families, and the healthcare system<sup>3,4</sup>**



**Long-term treatment adherence is crucial in successful management, but can prove challenging, especially in the younger population<sup>1,2</sup>**

# Treatment adherence can be challenging for many reasons

## Medication-related factors



Treatment or illness fatigue<sup>1</sup>



Long asymptomatic phases<sup>2,3</sup>



Complex dosing schedules/pill burden<sup>2,4</sup>



Fear of dependency or side effects<sup>2,5</sup>



Fear of needles<sup>2</sup>

## Psychosocial factors



Underestimating consequences of a chronic condition<sup>3,6</sup>



Patient-physician communication barriers<sup>2-4</sup>



Caregiver setting/family dynamics<sup>6,7</sup>



Peer stigma/feeling different from peers<sup>2,6</sup>



Adolescent wish for independence vs parental oversight<sup>6,7</sup>

# Adherence can be particularly challenging for adolescents due to psychosocial factors

Feelings and beliefs of adolescents with long-term conditions impact adherence, for example by:<sup>1</sup>

**Not believing they actually need** the medicine<sup>1</sup>

I feel fine, so why do I need to take my medicine?

Feeling **peer pressure** and a desire to fit in<sup>1</sup>

None of my friends have to have their days interrupted by needing medicine

Believing they are **invincible**<sup>1</sup>

I don't think my illness affects me very much

Experiencing **depression, anxiety, emotional distress**, and lack of social support<sup>2</sup>

Everything feels too stressful to keep on top of

**Not actually being ready** for the responsibility of managing treatment<sup>1</sup>

I know I should be old enough to deal with this, but I'm really unsure



**Additionally, caregivers continuing to assume responsibility for treatment can cause conflict with adolescents wishing to develop their independence<sup>1</sup>**

Patient speech bubbles are representative, based on reasons for reduced adherence from published references.

1. El-Rachidi S, et al. Hosp Pharm 2017;52(2):124–131; 2. Tesfaye W, et al. Adv Kidney Dis Health 2024;31(1):68–83.

# Real-world data highlights the impact of low treatment adherence in patients with chronic conditions

Only about 50% of patients with chronic illnesses in developed countries are adherent to their medication<sup>1</sup>

Adherence is similarly low in children and adolescents:<sup>1</sup> separate studies across a range of diseases\* reported adherence rates ranging from 23% to 48%<sup>2,3</sup>

**This is well below the widely-accepted definition of adherence (patients taking 80% or more of their prescribed medications as intended)<sup>4</sup>**

## Non-adherence is associated with:



Reduced quality of life<sup>4</sup>



Higher outpatient and inpatient medical costs<sup>5,6</sup>



Poor clinical response<sup>5</sup>

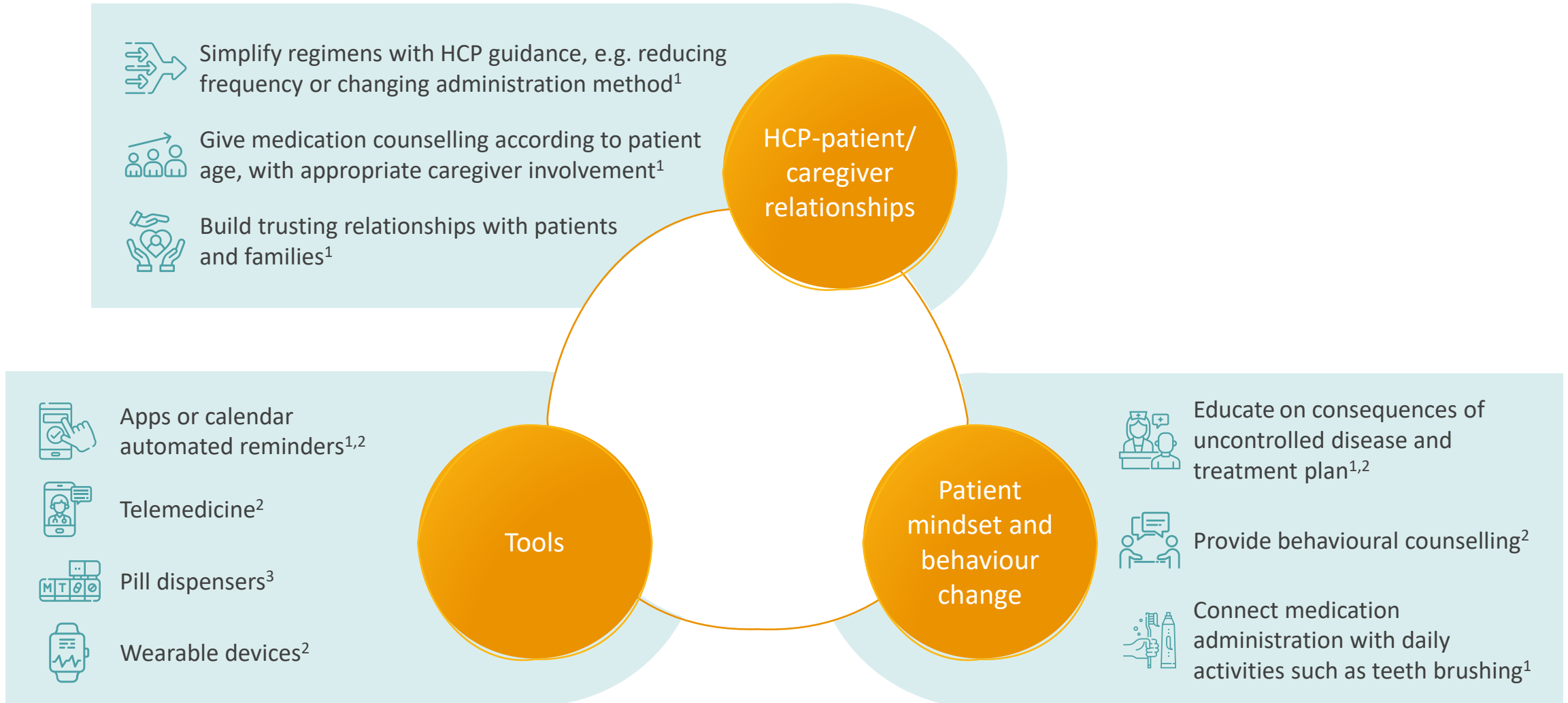


Increased hospitalisation and mortality risk<sup>5,6</sup>

\*Including children with glomerular disease,<sup>2</sup> adolescents using medications following liver transplant<sup>3</sup> and adolescents needing pulmonary medication.<sup>1</sup>

1. World Health Organization. Adherence to long-term therapies: evidence for action. Geneva: World Health Organization 2003; 2. Krissberg J, et al. J Am Soc Nephrol 2024; 35(10S):10.1681/ASN.2024qm0p14kc; 3. Taddeo D, et al. Paediatr Child Health. 2008;13:19–24; 4. Tesfaye W, et al. Adv Kidney Dis Health 2024;31(1):68–83; 5. Dingli D, et al. Poster presented at 2nd International PNH Interest Group (IPIG) Conference, May 15–16, 2025, Paris, France; 6. Sokol M, et al. Med Care 2005;43(6):521–30.

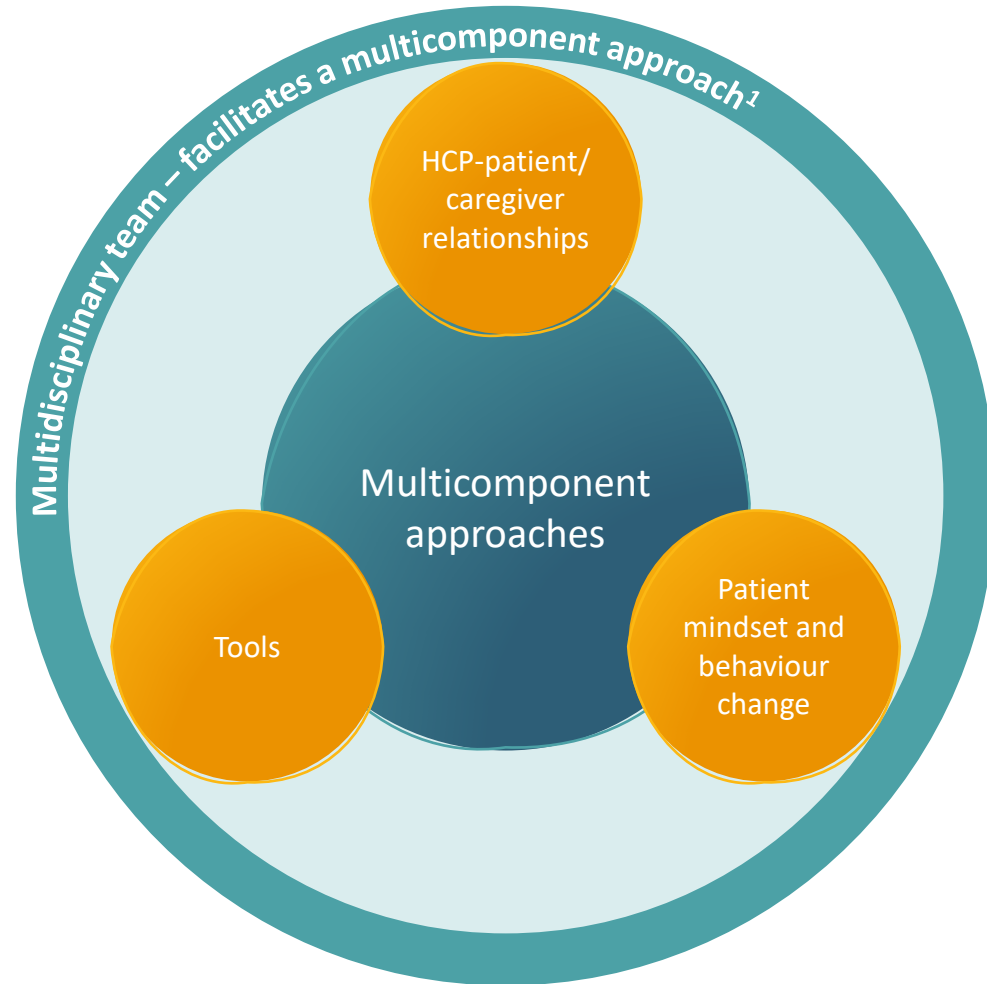
# Strategies that can aid adherence are available<sup>1,2</sup>



HCP: healthcare professional.

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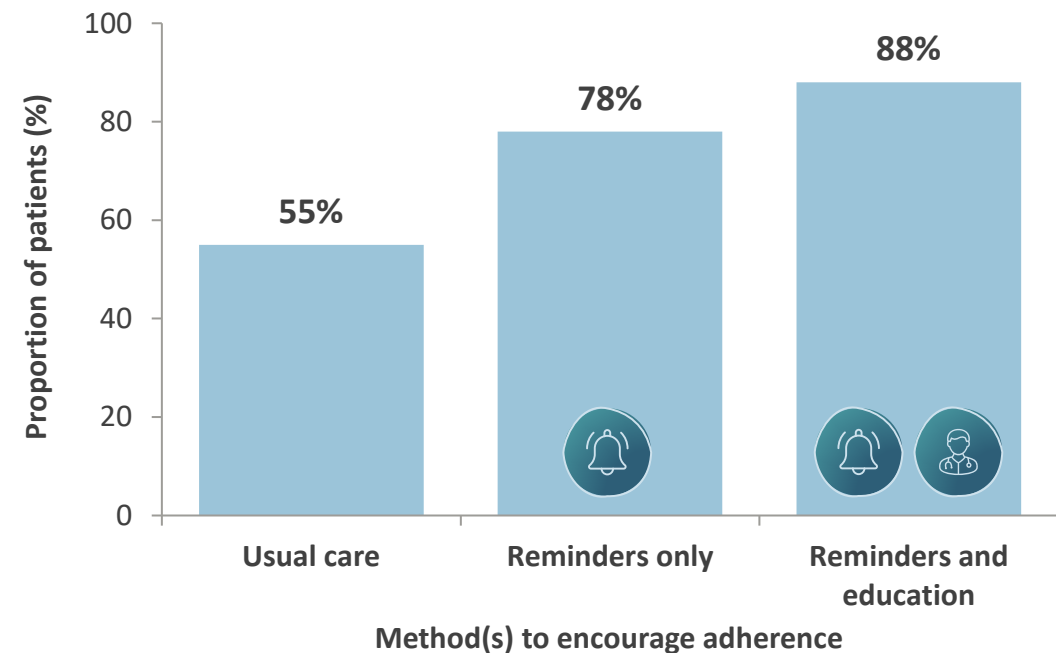
# Strategies that can aid adherence are available<sup>1,2</sup>



## Multicomponent approaches

Interventions using multiple strategies, for example, electronic monitoring alongside counselling, can improve adherence<sup>1</sup>

**In a study of 120 patients, using reminders and education together led to a significant improvement in adherence over 3–6 months compared to usual care and reminders only ( $p < 0.001$ ):<sup>\*3</sup>**



<sup>\*</sup>120 kidney transplant recipients or kidney-pancreas recipients at the Hospital of the University of Pennsylvania. 'Usual care': wireless pill bottle that tracked adherence only. 'Reminders only': wireless pill bottle that tracked adherence plus customized reminders (including alarms, texts, telephone calls, and/or e-mails). 'Reminders and education': wireless pill bottle that tracked adherence, plus customised reminders and provider notification (every 2 weeks, providers received notification if adherence decreased to <90% during that period).<sup>3</sup>

HCP: healthcare professional.

1. Tesfaye W, et al. Adv Kidney Dis Health 2024;31(1):68–83; 2. El-Rachidi S, et al. Hosp Pharm 2017;52(2):124–131; 3. Adapted from Reese P, et al. Am J Kidney Dis 2017;69(3):400–409.

# Collaboration is essential

In CKD, the MDT includes nurses, pharmacists, psychologists, nephrologists, and physicians. The MDT helps improve adherence by providing patient education<sup>1</sup>

The MDT is also crucial in the context of children and adolescents with chronic diseases for:<sup>2,3</sup>



**Acting as a bridge between child and adult services** at a time when physical, psychological, and emotional changes are at play, with the potential for reduced adherence if not carefully managed<sup>2</sup>



**Supporting parents:** a study of a British network of MDTs supporting children with CKD highlighted the **MDT's critical role in support for parents** who are learning to manage their child's CKD at home<sup>3</sup>

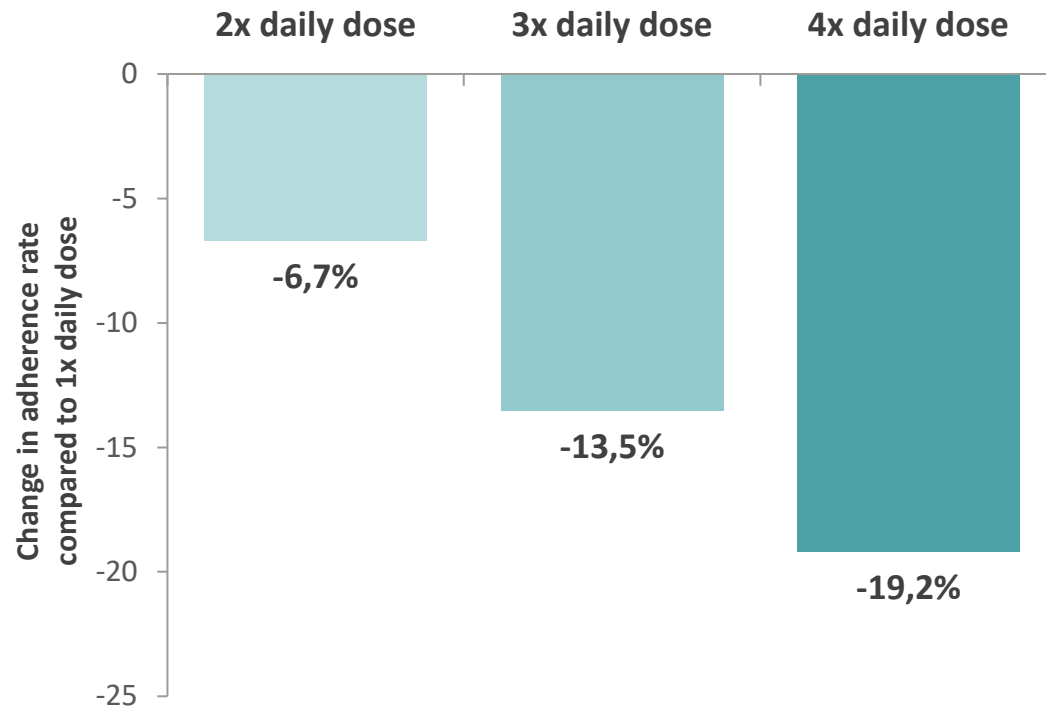
“A diagnosis of **childhood CKD can be devastating** for the whole family; it **requires extensive communication** and support to minimize anxiety and uncertainty, and the **renal MDT usually becomes the focus for parents to seek specialist support**, advice and guidance”<sup>3</sup>

# Medication types can impact adherence outcomes



## Oral medications can pose some adherence challenges

In chronic disease, the more pills in a treatment regimen, the lower the adherence<sup>1</sup>



Adherence to oral treatments can also be impacted by variables such as:



Drug-specific food requirements<sup>2</sup>



Physiological issues such as difficulty swallowing<sup>2</sup>



Dislike of taste or texture<sup>3</sup>



Belief that pills are not as effective as long-acting injectable medications in some chronic conditions<sup>4</sup>

PNH: paroxysmal nocturnal haemoglobinuria.

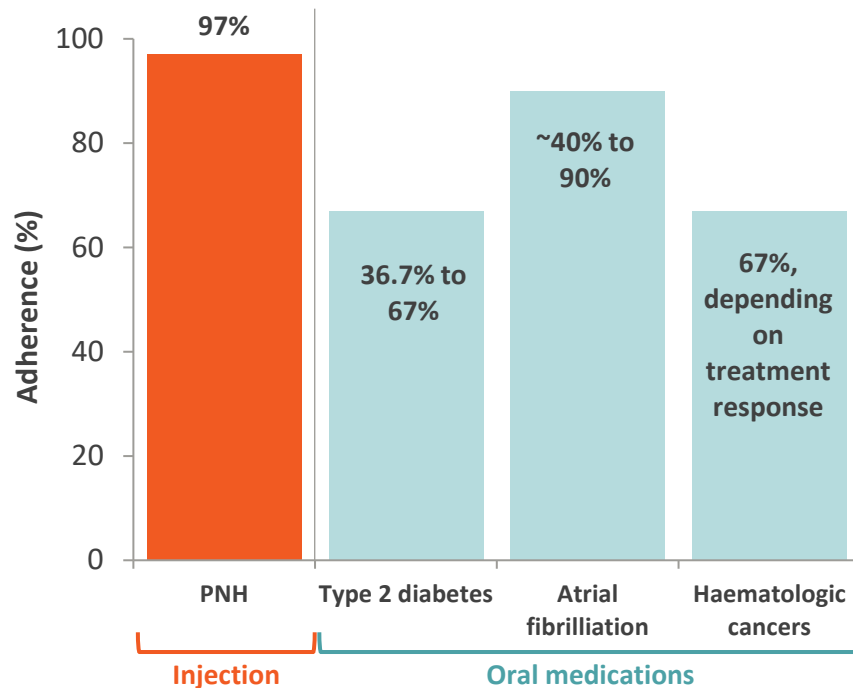
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# Medication types can impact adherence outcomes



## Injectable medications can help patients take medication consistently

Real-world data in PNH showed 97% adherence with **pegcetacoplan injection**. This was above the reported adherence rates for **long-term oral medications for other chronic conditions**:<sup>1</sup>



## Real-world study of PNH patients in the United States<sup>2</sup>

Patients switched from at-home SC injection and infusion pump to a wearable, single-use, SC pegcetacoplan injector

A preference for the wearable injector was reported due to ease of use, convenience, and lack of visible needle



## Wearable electromechanical devices can alleviate:

- **Needle phobia** – due to a hidden needle<sup>3</sup>
- **Discomfort of a jolt or click** – as medicine is released gradually<sup>3</sup>
- **Low adherence** – some devices can send auto-reminders<sup>3</sup>
- **High frequency dosing** – with longer-lasting effects allowing less frequent dosing (vs oral medications), daily life may be less disrupted<sup>4</sup>

PNH: paroxysmal nocturnal hemoglobinuria; SC: subcutaneous.

1. Adapted from Dingli D, et al. Poster presented at 2nd International PNH Interest Group (PIG) Conference, May 15–16, 2025, Paris, France; 2. Mulherin B, et al. Blood 2024;144:5673–5674; 3. Antalfy A, et al. Adv Ther 2023;40:4758–4776; 4. Milz Neuropsychiatr Dis Treat 2023;19:531–545.

# Conclusions



Adherence to treatment for a chronic disease can be difficult for lots of reasons, including feelings and beliefs about a disease or treatment and practical challenges<sup>1-3</sup>



Multidisciplinary teams should work closely with people with chronic diseases and their caregivers to understand and reduce barriers to adherence<sup>2,4</sup>



Adherence is not only about calendar reminders, it is remembering why staying on treatment matters, even if the person feels well – this is particularly important in CKD<sup>2,5,6</sup>

CKD: chronic kidney disease.

1. El-Rachidi S, et al. Hosp Pharm 2017;52(2):124–131; 2. Tesfaye W, et al. Adv Kidney Dis Health 2024;31(1):68–83; 3. World Health Organization. Adherence to long-term therapies: evidence for action. Geneva: World Health Organization 2003; 4. Scarponi D, et al. Front Pediatr. 2021;9:689758; 5. Kvarnström K, et al. Pharmaceutics 2021;13(7):1100; 6. Aljofan M, et al. Electron J Gen Med 2023;20(3):em471.