



Improving Choice for
Kidney Patients:
Five STEPS toolkit to Home
Haemodialysis

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Foreword

Improving choice for kidney patients is key to delivering high quality care. By optimising access to all home dialysis modalities we can ensure everyone with kidney disease requiring renal replacement therapy is offered a realistic choice when considering how and where they wish to receive their treatment, whilst providing opportunities for both commissioners and providers to utilise resources most effectively. This toolkit is for home haemodialysis.

The first step to empowering patients is to embed shared decision making and self-care at the heart of kidney services. This will enable patients to have more insight into managing their own condition, improving their ability to make informed choices, gaining greater control and improved health to best suit their own life. Self-care tasks in the context of haemodialysis may range from patients' recording their blood pressure or weight pre and post in-centre dialysis sessions, through to independent dialysis in the comfort of their own home. Creating an environment and culture which supports increased access for patients to all forms of dialysis will support independent decision making. Providing opportunities for patients to share skills and competencies to develop their understanding and confidence in all treatment options could result in patients choosing home haemodialysis (HHD) who may never have considered doing so or were initially not convinced that they would be able to do so.

The clinical outcomes from longer and/or more frequent haemodialysis sessions in the home are the main clinical argument for HHD being preferable to in-centre dialysis. For patients there are more immediate benefits afforded by HHD with greater independence, ability to work full time, reduced travel, easing of dietary and fluid restrictions and reductions in medications. Patients on HHD can organise dialysis around their lives rather than dialysis dictating how they live.



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Using this Toolkit

Who is it the toolkit for?

This toolkit provides advice to:

- Providers of Kidney Services
- Specialised and PCT Commissioners

It may also be of interest to patients and carers considering Home Haemodialysis

What does the toolkit provide?

Based on clinical evidence from an extensive literature review¹, examples of 'what works' from units with successful HHD programmes and patient experiences from a number of sources¹

The 5 STEPS set out:

- A generic stepwise approach to establishing a successful HHD programme
- The importance of self-care and patient support
- Practical tips for planning and achieving each step
- A Guide to Useful Resources

¹www.kidneycare.nhs.uk

STEP 1 Self-care for all

Patients can be involved in all aspects of their treatment, from tasks such as weighing themselves through to complete independence irrespective of the site or point of care. Self-care for all should be an underlying philosophy across all kidney services.

Task required	How to go about it
Understand the potential for self care	Kidney Care Networks to work with commissioners, patients and providers of kidney services to develop a self-care framework, defining various levels of competency, towards making self-care available for all.
Access to reliable patient education and information resources	Signpost useful sources of information e.g. NHS Choices and the National Kidney Federation
Facilitate shared decision making offering genuine choice for all treatment options	<p>Ensure consideration is given for all patients to choose their preferred place of treatment as part of initial and ongoing discussions. Open patient choice should be a key step as part of shared decision making. If a patient chooses home therapies, focus on how to make that work, rather than on obstacles, taking the following into consideration:</p> <ul style="list-style-type: none"> • Patient capability • Carer availability and capability (see Step 2) <p>Provide a 'choice room', a stand alone private room with operational equipment for all therapies where the patient and their family can discuss their choices in confidence with a health professional, and allow patients sufficient time to consider options and ask questions. Allow time for reflection, access to additional resources, health professionals, decision aids, information in appropriate formats and most importantly other patients, before making a decision.</p> <p>Discuss benefits and risks of choices. In particular, whilst remaining clinically safe, be less risk averse, inviting fully informed patients to accept the risks associated with HHD. Engage in ongoing dialogue with patients about their choices as they may change over time. Establishing fixed review times.</p> <p>Whereas HHD may not be suitable for all patients, the decision reached should be the result of a shared process taking full account of the patient's preferences.</p>
Peer support network	Provision of a peer support network can be very helpful in assisting patient choice. Peer supporters are patients and carers who have had first hand experience of living with dialysis. Selected patients and carers can receive specific training to become peer supporters for other patients.

STEP 2 Training and preparation

In order to support HHD, the self-care framework will set out a number of steps for both the patient and clinical staff. Each step will be clearly defined with timings, competencies and outcomes.

Task required	How to go about it
Demonstrate self-care to all	Improved determination and confidence may come from enabling patients to share experiences and compare levels of competency. It may result in patients deciding to try HHD who had previously been uncertain about their own ability or suitability to perform HHD. Seeing another patient performing self-care tasks can be a powerful tool
Identification of appropriate locations for training	Develop training stations near but separate from the main dialysis unit to support independence from in-centre dialysis whilst providing easy access to support for both patients and training staff. Provide designated stations in hospital and satellite units for self-care dialysis with independence for patients who use them e.g. flexible dialysis times. These stations can be used to incentivise self-care.
Set out agreed training programme as part of the patient care plan	Develop individual tailored training programme with an expectation of the patient being able to dialyse at home within 12 weeks The training programme will include flexible schedules that could be undertaken to suit the individual patients needs e.g. during evenings and weekends or increased frequency of sessions during the week
Involve carers and partners as appropriate	Carers and partners should have a clear understanding of the potential impact of the patients' chosen treatment and be involved in the agreed training plan. Whether the presence of carers or partner is required for a patient to perform HHD, or whether lone HHD is appropriate, requires discussion between each individual patient and their renal unit.
Establishing reliable vascular access	Vascular access ² should be established as per Renal Association guidelines. Tunnelled dialysis catheters are suitable for HHD for some patients in whom fistula formation has failed.
Maximising safe methods for managing fistulae	Positive approaches to support the patient managing their own fistula should be in place, including self-needling, using the most appropriate method for the individual patient. Button hole ³ needling is considered the preferred method as this technique, when established, allows the use of blunt ended needles to gain repeated reliable access to the fistula, avoiding repeated standard fistula puncture.

² www.renal.org/home.aspx

³ Utility of the buttonhole cannulation method for hemodialysis patients with arteriovenous fistulas. Twardowski ZJ, Nat Clin Pract Nephrol 2007 3(12) 648-9

STEP 3 The Environment

If a patient wishes to progress to full self-care Haemodialysis at home, here is a checklist to ensure that the home environment is suitable for HDD.

Task required	How to go about it
Undertake initial assessment of the patient's home	<p>This should be undertaken by renal technicians or local contractors to review with the patient the preferred place for the equipment, taking into consideration:</p> <ul style="list-style-type: none"> • Space required for the dialysis machine, chair and reverse osmosis unit • Type of waterproofing measures • Storage space for needles, fluids, day packs • Choice of machine (newer equipment may offer solutions for houses which are unsuitable for standard dialysis equipment conversions See step 5)
Ensure development of required contractor relationships	<p>Successful relationships are required to support the provision of dialysis in a patient's home. These may be developed independently, however many units find it easier to use a single point of contact.</p>
Water supply	<p>Initial assessment by contracted plumber to check aspects of the water supply such as water pressure, availability of supply in the proposed dialysis space and if the supply is metered.</p>
Electric	<p>Initial assessment by contracted electrician to make assessment and provide advice on changes that may be necessary.</p>
Telephone	<p>Initial assessment by contracted provider as 24 hour telephone support is required.</p>
Installation	<p>The training programme should identify the key point, signifying satisfactory progress, for initiating equipment installation provided the assessments outlined above are satisfactory.</p> <p>Once location has been determined, responsibility for installation can vary between in-house responsibility (e.g. estates departments) and private company tender. This should be identified in the agreed plan.</p>

STEP 4 Providing Support

Once equipment is installed, training is complete and HHD is established, a number of supporting activities need to also be in place to ensure the safe and continuous running of HHD. In particular, ongoing support for the patient, and where applicable their carer, is vital.

Task required	How to go about it
Clarification of access to clinical and technical support	<p>All patients who dialyse at home will need access to 24 hour clinical and technical support in the event of an untoward incident or emergency. This may be a single point of dedicated support or shared with an agreed out of hours plan.</p> <p>The patient should be registered as a HHD patient with their water, electrical and telephone suppliers in case of supply failure.</p> <p>The patients individual care plan should include clear contact arrangements.</p>
Agree with patient how monitoring will be undertaken	<p>Ensure the care plan has clear arrangements for monitoring to be undertaken. This may include:</p> <ul style="list-style-type: none"> • Monitor vascular access in line with unit policy • Blood samples posted securely on monthly basis by the patients • Planned formal follow up as desired • Regular review of satisfaction with chosen treatment option • Access to respite care • Using Renal Patient View
Home Therapies Team	The most successful units have dedicated staff for home therapies, skilled in training, monitoring and support.
Materials	Support materials can be delivered by the community team. Removal and disposal of used supplies will need to be organised.
Equipment maintenance	Technicians or local contracted providers maintain and upgrade equipment and deliver products as required.
Support networks	<p>Access to an appropriate peer support network can be helpful in preventing HHD patients feeling isolated.</p> <p>This applies equally to carers who often combine a larger share of household duties with HHD assistance.</p>

STEP 5 Sources of Funding

In order to begin plans for HHD, there must be a clear and detailed understanding of the costs, where they occur and what sources of funding are available. The largest of these costs are undoubtedly the set up and training costs and these are often perceived as barriers to HHD.

Task required	How to go about it
Gaining Trust Management sign-up and engagement with Commissioners	<p>Provide business case to demonstrate potential impact locally for increased number of patients on home haemodialysis. Key elements may include:</p> <ul style="list-style-type: none"> • The cost of providing future in-centre capacity (hospital or satellite) • The set-up costs (training and installation) • Cost benefits of reductions in travel (including carbon footprint), medications, staffing/overhead requirements, ability of some patients to return to work • Ongoing costs for monitoring and quality assurance
Clarification regarding local arrangements to secure set up costs for training and installation	<p>At present units use different funding models and there is no standard model. Proposed non-mandatory dialysis tariff will be on a full absorption basis.</p> <p>Typical installation costs are £3500 to £5000 but can vary outside this range depending on local factors. Training costs need to be calculated locally. Contact established programmes for advice.</p> <p>There is no definitive period that can be evidenced as to when the set-up costs are recouped, but available evidence as referenced by NICE⁴ suggests 14 months</p> <p>Considerations include:</p> <ul style="list-style-type: none"> • Refurbished versus new machines • Leasing versus owning machines • Outsourced versus in-house installation • Training
Clarification regarding covering ongoing costs to the patient	<p>Costs incurred by the patient as a result of HHD will need to be monitored and reimbursed by the host Trust². These include:</p> <ul style="list-style-type: none"> • Electricity • Water (if metered) • Telephone
Understanding the funding sources	<p>The proposed non-mandatory tariff is based on statutory Reference Costs Returns made by Trusts providing an indication of the price for dialysis regardless of setting. The Reference Costs are set up to be full absorption inclusive of capital expenditure such as training or buildings.</p> <p>PbR Guidance⁵ recommends applying the prices per haemodialysis session to each session of home haemodialysis, while acknowledging that patients dialysing at home may wish to have four or five sessions of dialysis a week. There should be no cap of the number of patients having access to home haemodialysis or the total number of home HD sessions that can be prescribed. Discussions between commissioners and providers should help balance any financial risk</p>

⁴ National Institute for Health and Clinical Excellence (NICE) Technology Appraisal Guidance – no 48 (TA48) *Guidance on home compared with hospital haemodialysis for patients with end stage renal failure 2002*

⁵ http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Selecteddiscontinuedseries/DH_076858?

⁶ www.dh.gov.uk/pbr

Resources

Resource	Relevance
1. Professionals:	
Department of Health Available from: www.dh.gov.uk	The National service framework for renal services provides a background on the service delivery standards, quality requirements and markers within existing renal services, and includes sections on markers related to patient-centred care and choice. <i>Achieving Excellence in Kidney Care</i> - Delivering the NSF for Renal Services highlights progress over the five years since the publication of the National Service Framework
NICE Guidelines Available from: http://www.nice.org.uk/guidance/ta48	Guidance on home compared to hospital haemodialysis for patients with end stage renal failure. (Sept 2002)
NHS Kidney Care Available from: www.kidneycare.nhs.uk	Provides resources and access to information across the entire kidney care pathway including: <ul style="list-style-type: none"> • <i>Improving Choice for Kidney Patients : Home Haemodialysis</i> • Toolkit : 5 Steps to Home Haemodialysis • Videos on patient experience • Examples of 'What Works'
Renal Association Available from: www.renal.org/home.aspx	The professional association of nephrologists (renal physicians) and renal scientists in the UK. Recent reports have been published on home haemodialysis and peritoneal dialysis.
UK Renal Registry Available from: www.renalreg.com	A resource providing independent, professionally led, audit and analysis of renal replacement therapy (RRT) including interactive geographical maps of the UK.
NHS Evidence - kidney diseases and male urogenital disorders Available from: http://tinyurl.com/ycfr5bn ,	Link to references selected by date and evidence quality for the kidney diseases and male urogenital disorders specialist collection
Centre for Evidence based Purchasing (CEP) www.kidneycare.nhs.uk	1. Home Haemodialysis – A guide for commissioners 2. Technology assessment – portable dialysis machines (Available from March 2010)
Guy's and St Thomas' Charity: Modernisation Initiative http://www.gsttcharity.org.uk/grants/results_mikidney.html	Resources produced to support self care education as part of the Modernisation Initiative funded by Guy's and St Thomas' Charity to re-establish self care in ten HD units across SE London.
Association of Renal Technologists (ART) Available from: www.artery.org.uk	Access to resources and examples of good practice for technicians in kidney services.

Resources

Resource	Relevance
2. Patients and Carers:	
Renal Patient View (portal) https://www.renalpatientview.org	This secure NHS site allows renal patients to view their test results and access details regarding their local clinic.
NHS Choices (2008) Available at: www.nhs.uk	NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make choices about your health with specific information related to kidney care.
Guy's and St Thomas' Charity: Modernisation Initiative http://www.gsttcharity.org.uk/grants/results_mikidney.html	As part of the Modernisation Initiative, a three year project was funded by Guy's and St Thomas' Charity, to re-establish self care in ten HD units across SE London. Resources were produced to support self care education and are freely available via the link provided
National Kidney Federation Available at: www.kidney.org.uk	The National Kidney Federation's aim is to promote both the best renal medical practice and treatment, and the health of persons suffering from Chronic Kidney Disease (CKD) or Established Renal Failure (ERF). The NKF also supports the related needs of those relatives and friends who care for kidney patients.
World Kidney Day Available at: www.worldkidneyday.org	World Kidney day is a joint initiative of the International Society of Nephrology (ISN) and the International Federation of Kidney Foundations (IFKF). The mission of World Kidney Day is to raise awareness of the importance of kidneys to our overall health and to reduce the frequency and impact of kidney disease and its associated health problems worldwide.
Kidney Health Australia Available at: www.kidney.org.au	A website with valuable information for patients and for Health professionals.

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