

Addenbrooke's Kidney Patients Association (AKPA)

H A N D B O O K



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For AKPA Freepost and Website addresses – see back cover; other contact details and useful links are on a separate sheet supplied with this handbook.

Addenbrooke's Kidney Patients Association (AKPA)

Who are we?

AKPA was founded in 1975 by a small group of patients; we now have members throughout East Anglia and beyond. Our membership includes dialysis, pre-dialysis and transplant patients as well as relatives, friends, nursing and medical staff.

AKPA is a registered charity, run by an Executive Committee elected by association members at our Annual General Meeting. Committee members are also trustees of the charity and are all volunteers; this keeps our administrative costs low (over 90% of funds raised go towards helping patients). Members of the nursing staff are also on the committee to advise on medical matters.

We are affiliated to the **National Kidney Federation (NKF)**, an umbrella group for all Kidney Patients Associations, which takes up issues affecting kidney patients at a national level.

The main purpose of AKPA is to help improve the quality of life for people suffering from kidney disease and to inform the public of patients' needs.

We are involved in a wide range of activities including occasional social events and talks by hospital staff on medical advances. The Association campaigns to improve conditions for kidney patients and to promote the **Organ Donor Register**.

How do we raise our funds?

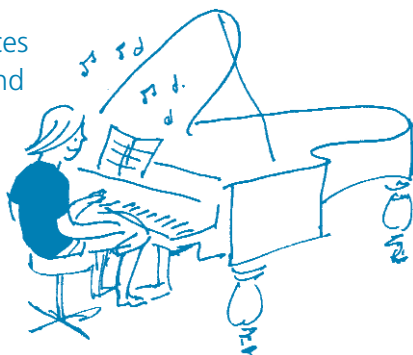
This is mainly down to members of AKPA, their families and friends, with help over the years from many other individuals and organisations who have taken an interest in our work.

To achieve our aims we constantly need to raise money and the range of sources is wide.

- Sponsored events, such as cycle rides, golf tournaments, clay-pigeon shoots, walks, swims, even a vintage tractor rally.



- Charity entertainment events such as dances and concerts, coffee mornings, art sales and car boot sales.
- Street and supermarket collections, and charity boxes in shops etc.
- Christmas card sales.
- Annual subscriptions.
- Seasonal craft and bric-a-brac stalls.
- Christmas raffle.
- A 200 Club with monthly draws.
- Bequests, legacies and donations in memory.



If you can organise or assist with any of the above, or have any original ideas for fund-raising, please contact any Committee member or your Dialysis Unit.

AKPA can help with advice, and can also provide posters, collecting-boxes, Donor Registration Forms, sponsorship forms and other useful materials.

We are always looking for **any** help, however small.

How do we use our funds?

Regular commitments

- Funding a **Renal Welfare Officer**.
- Welfare grants.
- Financial assistance for holidays.
- Producing *Newsflash*, a regular newsletter for members.
- Help with expenses for members attending the annual NKF Conference.
- Supporting the Transplant Games.

Special projects

Past and ongoing support includes:

- Purchasing equipment and comforts for Addenbrooke's Dialysis Centre, Renal and Transplant wards and for the Satellite Units, for example, reclining dialysis chairs, a TV system for patients and air-conditioning.

- Funding research projects at Addenbrooke's Hospital.
- Initiating the Skin Surveillance Programme for transplant patients.
- Paying the costs of making an exercise video for PD patients.
- Providing a Transplant Clinic Nurse.
- Support for medical and nursing staff to attend training courses and international conferences.



We believe that our association does a valuable job in supporting patients, their families and the superb medical and nursing teams at Addenbrooke's and the Satellite Units.

We welcome new members

If you would like to join **AKPA** or learn more about us please look on our website **www.akpa.org.uk**; or complete and return a membership form (normally available in the Dialysis Centre); or write to our freepost address; or email us. Freepost and e-mail addresses are on the contact sheet with this handbook).

The suggested subscription is voluntary, as we realise that some patients cannot afford to pay. The amount suggested is to cover our administration costs, however we are very grateful for any donation you can afford to make.

The AKPA Committee feels the information contained in this booklet may help you understand some of the problems, hopes and concerns of being a kidney patient.

If you have a problem and would like to talk to someone please do not hesitate to contact us. If we are unable to help we may be able to direct you to other sources of advice and information for kidney patients and their families. For contact details see separate sheet.

Publicity

If the general public do not know of us they cannot support us. Members and friends of **AKPA** can help with publicity in a variety of easy ways:

- *A quick phone call* to our **Publicity Officer** (please see enclosed contact sheet for details) when you hear of local events involving patients and their families, kidney patients' successes and fundraising achievements.
- *Local newspapers, magazines, radio and TV* like to carry stories about patients, carers, fund-raising and organ donation. Our Publicity Officer can advise and help with useful contacts.
- *Using the AKPA display at your event* – we have a portable display promoting donor registration and explaining what AKPA is all about, and banners for mounting over sales tables.

Newsletter

Newsflash is our award-winning Newsletter. It is published regularly to help widely-scattered members keep in touch with their Association and each other. Like all our activities it relies on the members themselves to provide the impetus and the material; so if a funny thing happened to you on the way to your Dialysis Centre or you have a useful tip on dialysing, discovered a helpful holiday hotel or even have a horror story to relate, please share it with us. Contributions should be sent to the **Editor**. (Please see enclosed contact sheet for details.)

AKPA Website

For those with internet access, our website, **www.akpa.org.uk** is full of the latest news and useful information for Addenbrooke's renal patients. It includes an online version of *AKPA Newsflash*; advice and information for patients; the latest fundraising news, plus a list of contacts and links to other useful websites – and much more. Try it out.



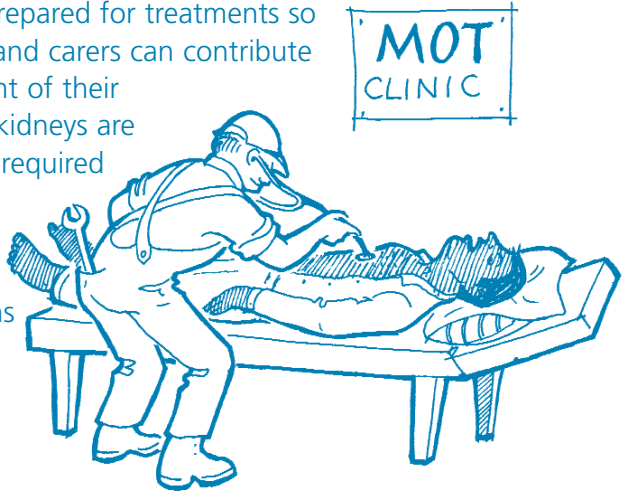
Treatment for Kidney Failure

Kidney Function

Normal kidney function is a very complex process. Waste products are filtered from the blood by the kidneys and are eliminated together with excess fluid as urine via the bladder; however the kidneys also regulate other important functions in the body, including blood pressure, hormones and haemoglobin (red blood cells), and they play an important part in maintaining healthy bones. When the kidneys fail to perform adequately, treatment becomes necessary and this may include one of the types of dialysis.

Patients are educated and prepared for treatments so that they and their families and carers can contribute positively to the management of their condition. The phase when kidneys are failing but dialysis is not yet required is often known as 'low clearance'. In this situation drug regimes may be used to ensure the patient remains as healthy as possible.

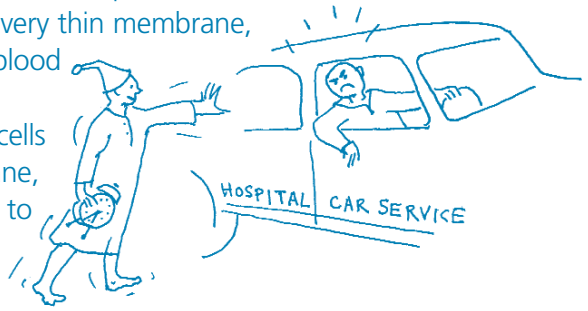
Eventually the patient may start one of the types of dialysis. Not all patients may benefit from dialysis however and the options and treatments will be discussed with each individual person.



Haemodialysis (HD)

For haemodialysis an artificial kidney (dialyser) is used to filter the blood. Access to the bloodstream is required, so that blood can pass through this dialyser on the dialysis machine. An access, known as a 'fistula', is made, usually in the arm.

Using a special fluid called dialysate, waste products are filtered from the blood through a very thin membrane, which has tiny pores (holes). The blood flows past the membrane; waste particles pass through, but blood cells are too large to cross the membrane, and the cleaned blood is returned to the patient.



Patients have haemodialysis two or three times a week for three to four hours, depending on individual needs. This takes place at Addenbrooke's Dialysis Centre or one of its Satellites.

Home haemodialysis

Home Haemodialysis means that you have a kidney machine installed in your home so that you can carry out dialysis with the help of a partner, such as your spouse or parent. You dialyse three times a week using this equipment, therefore taking responsibility for your own treatment.

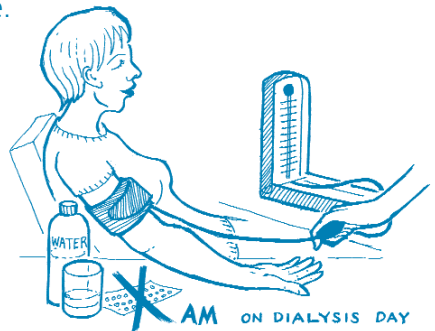
To be considered for Home Haemodialysis you must be fit and well whilst on dialysis, be able to needle yourself, have a caring, capable partner to help you and a spare room in your home, which can be converted for dialysis use.

Home Haemodialysis can give you more independence as it is fitted around your family life style.

Peritoneal Dialysis (PD)

PD can be fitted around normal daily activities, for example in the home or the workplace.

In this kind of dialysis, a special fluid (dialysate) is run into and out of the abdomen (peritoneal cavity) via a small tube. This soft, permanent tube (Tenckhoff catheter) is inserted through the abdominal wall into the peritoneal cavity during a short operation. The peritoneal membrane (peritoneum) which

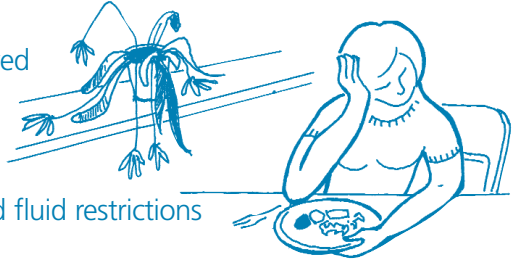


lines the abdomen is used as a filter to draw out waste products and excess water from the blood.

This is done manually, on average 2 to 4 times a day. Some patients may use an APD (Automated PD) machine which is pre-programmed to carry out the exchanges overnight during sleep.

Diet

In recent years dialysis has vastly improved and most people maintain a very good quality of life. However both forms of dialysis are less efficient than normal kidney function, so appropriate diet and fluid restrictions may be necessary.



In fact, diet is a very significant part of the treatment and management for many people with kidney problems. A patient may need to follow a special diet, or at least eat in such a way as to maintain a balanced nutrition.

The Dietitians assess each patient individually to decide on the most appropriate diet. This depends on blood results, type of treatment, urine output, the kinds of food you prefer to eat and any other dietary restrictions you may have, for example for diabetes.



Dietitians are available to advise all renal patients, if you would like to see a dietitian to discuss your diet, then please ask the nursing staff.

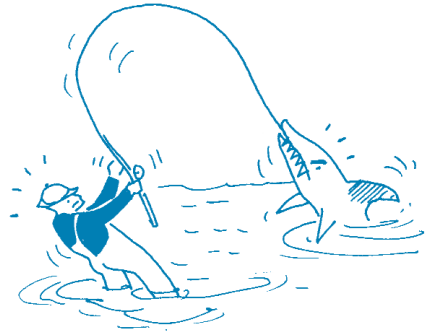
Holidays and Short Breaks

Holidays on haemodialysis

Short breaks can be taken between haemodialysis sessions.



Longer holidays in the UK and abroad are quite possible for patients and their families, so long as arrangements are made to use another Dialysis Unit at the destination. Holidays can usually be arranged once a patient has been stable on haemodialysis for six months or more.



When choosing a holiday destination, the staff at the Dialysis Centre will advise

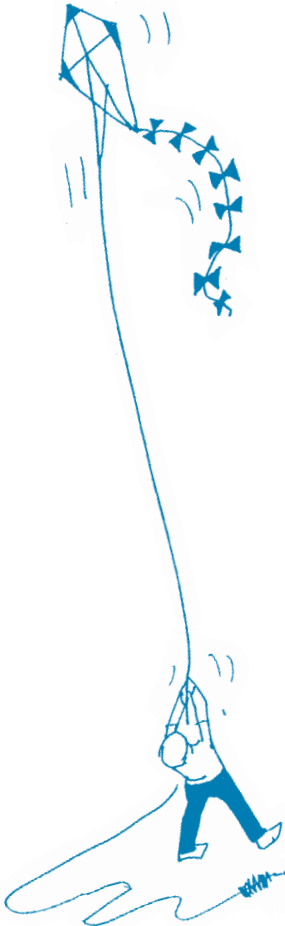
about the nearest dialysis facilities in that region and check if space is available at the times requested. The **British Kidney Patients' Association (BKPA)** has its own holiday dialysis centres or can recommend ones which they have inspected. It may also be possible to join an arranged group holiday.

- 6 – 8 weeks notice is required of the intention to take a holiday.
- It is usually easier to arrange holiday dialysis abroad than it is in the UK.
- Flights and accommodation should not be booked until dialysis slots are confirmed.

Holidays on PD

It is possible to go almost anywhere in the world on PD. The PD nurses can arrange with the manufacturers to deliver dialysate supplies to the destination of choice. However, plans must be made in advance to arrange for storage and for somebody who will accept the delivery before your arrival. Patients who have appropriate transport may be able to take their own supplies.

- Plans should be discussed well in advance with the PD nurses, as arrangements take some considerable time.
- At least 8 – 12 weeks notice of a trip abroad or off the UK mainland is needed, and 2 – 4 weeks for an inland UK visit.



Transplantation

For many patients this gives an opportunity for the return to a normal lifestyle.

A transplant can offer release from dialysis and from dietary and fluid restrictions. However it should be borne in mind that not all patients are medically suited to receive a transplant.

The success of transplantation

Figures from **UK Transplant** show that currently, 87% of kidney transplants are working after one year. Results continue to improve, as shown by the fact that 50% of kidney transplants now last over 10 years.

UK Transplant, which is a special Health Authority within the NHS, oversees and monitors the whole process nationally. It ensures that donated organs are matched and allocated in a fair and unbiased way.

Organ rejection is always a factor in transplantation and immense efforts are continuously put into the search for improved anti-rejection drugs. Much of this work takes place in Cambridge and the AKPA assists with the funding of some of this important research.

Organ donation

Kidneys may be donated from one of two sources, either after death or from a living donor. In either case there are very thorough and careful procedures to be gone through.

Donation after death

When someone has suffered severe and irreversible damage to the brain, organ donation may be possible. If death is confirmed by a series of well-established tests performed at the bedside by two senior doctors who are not part of the transplant team, or if death is the expected outcome, families are given the opportunity to discuss the option of organ donation with a member of the Transplant Coordinator Team. This decision is often easier for families to make if the wishes of their relative have been made known in advance. One way for this to happen is through the **NHS Organ Donor Register** (Organ Donor Line number – 0845 6060400).

Live donors

A kidney may be successfully transplanted from a living person (usually, but not necessarily, a close relative such as a parent, brother, sister, or a partner). The pros and cons are discussed with the family at length and the process of preparation for the donor takes several months. The donor is never put under pressure and has many medical checks to ensure he/she is fit, and that his/her kidney is a close match for the recipient. Emotional and psychological support are always available.

The future

There is a worldwide shortage of organ donors and a consequent need to increase the number of kidneys donated.

In July 2000 UK Transplant was given the additional aim of increasing organ donation rates. The public and media still need to be better informed about transplantation. Organisations such as AKPA work hard to increase awareness and understanding in the public and by encouraging people to add their names to the national Organ Donor Register.

Transplant coordinators

Transplant Coordinators play a vital part in ensuring that organ donation and transplantation go as well as possible.

There are **Donor** and **Recipient** Transplant Coordinators.

The main role of the **Donor Coordinator** is to ensure families are given an informed choice when considering organ donation, that they are guided through the process of donation, and the intentions of the deceased are carried out.

This involves liaising with other health professionals such as surgeons and with recipient centres. The Coordinator supports both family and staff and will continue to do so post-donation for as long as is needed.

Recipient Coordinators maintain the database of patients waiting for a cadaveric organ (the organ of a donor who has died). Patients are assessed annually or six-monthly for fitness to receive a transplant. Sometimes patients are advised that having a transplant may not be the best treatment for them, so they do not join the waiting list.

Living Donor Recipient Coordinators are involved in preparing, both medically and psychologically, family and friends, husbands and wives for living donation.

Addenbrooke's Coordinators liaise with other eastern region Recipient Coordinators because patients from hospitals throughout the region have their transplant operations at Addenbrooke's Hospital.

The medical staff and coordinator attend pre-transplant clinics in the referring hospitals so that patients can be seen at their own hospital. Once the patient is stable after a transplant, usually within a few months, outpatient care is transferred back to the patient's hospital. The Recipient Coordinator continues to see newly transplanted patients in weekly follow-up clinics.

Both Recipient and Donor Coordinators also play very active roles in professional and public education, to raise awareness of Organ and Tissue Donation.

Transplant games

Aim to:

- encourage public awareness of organ donation
- encourage transplant patients to live life to the full
- give thanks to organ donor families



Organised under the auspices of the Transplant Sports Association of Great Britain (TSAGB), the Games were the brainchild of Professor Maurice Slapak, a renal transplant surgeon. They were first held in 1978 as a one-day event; their success has since seen them expand into a four-day event with hundreds of participants.

The Games include bowls, volleyball, table tennis and darts as well as the usual athletic events. They demonstrate the success of transplantation and illustrate the participants' ability to live an active life. The games would not be possible without the generosity of the donors and their families.



AKPA supports individual kidney transplant patients who take part in the games as part of Addenbrooke's team by giving grants towards travel and accommodation costs.

Patient Welfare

A major function of **AKPA** is to help members who are going through a period of difficulty. To assist in this we fund a Welfare Officer who is available to give advice and help to patients and their families.

Renal Welfare Officer

(Please see enclosed contact sheet for details.)

Benefits and allowances are a complex issue and are constantly changing.

Our Renal Welfare Officer has extensive experience and knowledge of the social and financial difficulties that may be encountered by renal patients. The Officer is very happy to act on behalf of patients, for example by making contact with government departments.

If funding is not available elsewhere **AKPA** can, on the recommendation of the Renal Welfare Officer, consider various grants. These include help with heating, holidays, the cost of hospital visiting and utility bills. All requests are carefully considered in confidence and on their own merits.

For more advice and help on these and similar issues, please contact the Renal Welfare Officer.

Renal counsellor

(Please see enclosed contact sheet for details.)

Kidney failure can be a traumatic experience and professional counselling is available for those who feel it would be beneficial. This can be arranged by contacting the counsellor directly or through the staff at the Dialysis Centre, Satellite Units, wards and renal clinics.

Confidentiality will be maintained whatever the route of contact.

AKPA

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