

LIVING WITH RENAL FAILURE | ISSUE 2-2019

share_{for}care

HEALTHY LIFESTYLE

Balsam for body and soul:
The Chinese way

A PATIENT'S STORY

Someone who never gives up:
The journey of an athlete

RECIPE

Asian sweet &
sour chicken

TRAVEL STORY

DOWN UNDER

Australia's fascinating mix
of wild and wonderful



Dear readers,

It's known from scientific studies that medical treatments are particularly successful when patients play an active role in promoting their own health.

But we can help ourselves with regular exercise, a healthy diet, and relaxation — it's important to take responsibility for your own life. To achieve this, it's essential to understand your condition and the treatment steps that are needed.

So, it's good that you've got this new issue of *share for care* in your hands: if you are looking for information, trying to stay on the ball, and wanting to discover what is important for you, then we hope to provide you with information and tips on living with chronic renal failure.

You're sure to have wondered already what actually happens during home hemodialysis. This issue's special topic explains how this treatment option — which is specially aimed at patients who want to take independent responsibility — works, and what the advantages and challenges involved are.

You can also read about how you can support the people helping you, whether family or friends; why you should renew your flu vaccination; and how you absolutely must give the magical slow-motion exercise art of Qi Gong a try, as a way of improving your well-being.

If you're keen on faster types of exercise such as running, for example, you'll be interested in this issue's patient story, all about Róbert Gelencsér from Hungary. The enthusiastic and competitive sportsman has been living with the diagnosis of renal failure since he was 13. He's convinced it was the exercise provided by his ambitious running that kept him going through the years when he needed dialysis and which helped him recover quickly after kidney transplantation. And he's justified by his success: today, Gelencsér has a happy family life and has already been named as Hungarian para-athlete of the year twice. It is role models like Róbert, who encourage others in their own steps toward achieving more activity and joie de vivre — no matter how small the steps may be to start with.

We hope that you find this edition of *share for care* rewarding and enjoyable. To complement this issue's information about diet and fitness, why not download the Renal Care Compass app, which you can install on your smartphone easily and free of charge?

Wishing you an enjoyable and active time!

Yours,



Christopher Boeffel



Martin Kuhl

share for care

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A visit to the continent of Australia won't turn your world upside down.

LESS MEDICATION IN HOME HEMODIALYSIS

Patients who use a dialysis machine at home need around 30% less medication than patients in the renal care center. In particular, they manage with fewer tablets for reducing blood pressure and with lower phosphate-binder requirements. This was shown by a study on drug intake that compared a total of 236 dialysis patients. On average, an in-center dialysis patient needed 16 pills a day, whereas a hemodialysis patient only needed 10 to 11 pills a day.

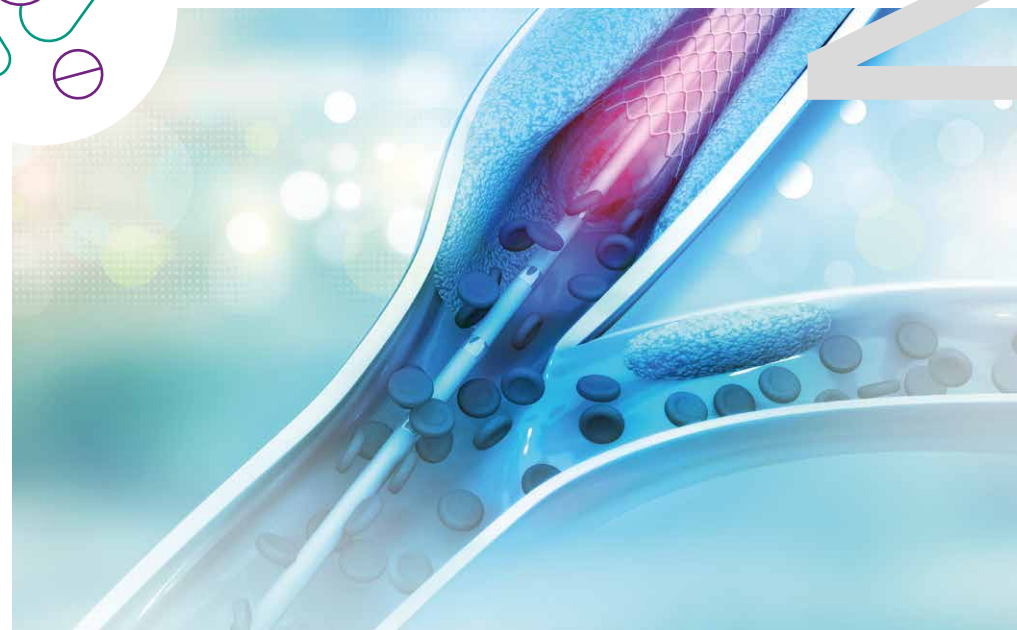


BLOOD VESSELS FROM THE LABORATORY

When blood vessels become damaged in dialysis patients, the approach used so far has been to transplant donor vessels or use synthetic blood vessels. All of the previous solutions available are associated with risks of rejection, breakdown, and infection. For the first time, blood vessels have now been suc-

PROMOTING OCCUPATIONAL ACTIVITY

Dialysis patients who are able to continue working are healthier and could have a longer life expectancy than those who lose their jobs during the course of treatment. According to a recent study, the social integration that work involves can lead to better self-esteem, and fewer financial worries all have a demonstrably stabilizing effect on physical health. If possible, patients who are able to work should therefore receive appropriate forms of treatment that enable them to combine work with dialysis.



cessfully generated in the laboratory. To achieve this, the researchers freed the genetic material from all original cells that might be recognized as foreign by the immune system. After being implanted into the recipient's body, the vessels generated in the laboratory developed like endogenous tissue and

did not lead to any rejection reactions or immune system reactions in any of the dialysis patients taking part in the study.

NEWS



TRACING THE genes

To help us understand the causes of kidney diseases better, scientists have analyzed data from more than a million participants in a large-scale international research study. The results identified 166 previously unknown risk-associated gene locations and 11 genes that are particularly important for kidney disease. The findings may be helpful for drug development and prevention programs among other things, and they could also open up completely new treatment approaches.





HOW DOES home hemodialysis work?

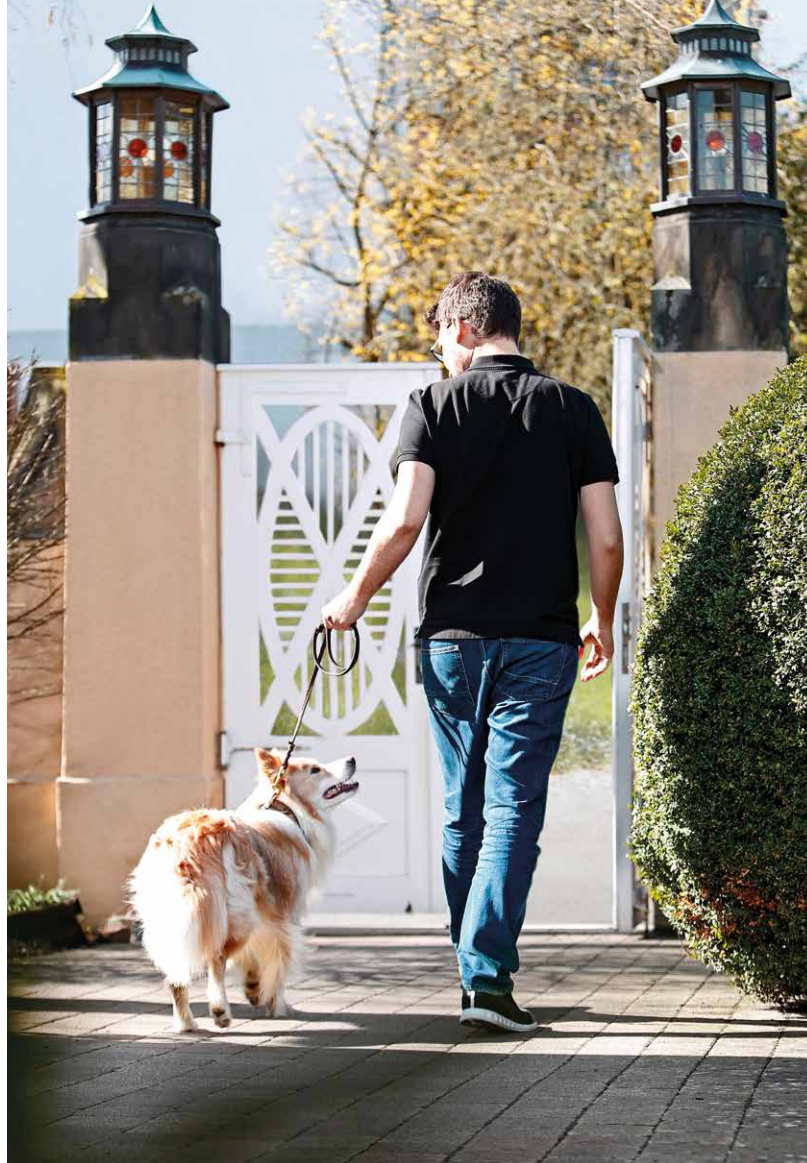
Dialysis within your own four walls is an attractive option for active patients who have work commitments and are able and willing to take responsibility for their own treatment.

The biggest advantage for patients of having the dialysis machine located in their own homes is obvious — patients are able to fit the blood-cleansing procedure into their everyday routines just as they wish and need. Patients who decide to have home hemodialysis are often very independent-minded and are therefore willing to accept the challenges that this type of treatment involves. "I can go home first, enjoy the day and the evening, and then start on dialysis," says one patient as he describes his new daily routine. "My quality of life is so much better! I wouldn't want it any other way now."

Being able to arrange the day freely and independently is a decisive point, particularly for patients who are working. They also have the option of being able to do exactly what they want during dialysis: they can wear what they like, talking quietly or loudly to friends on the phone, or listening to music — with all the freedom that only their own personal private space can offer.

On the other hand, patients — usually along with their partner or a family member acting as "dialysis care partner" — actually have to play the main role in their treatment: operating the dialysis machine, documenting the procedure, and also puncturing the arteriovenous (AV) access. No nurses are present. The treatment material needed is delivered at regular intervals, and all of the technical devices are installed and regularly maintained by renal care center staff. A medical emergency phone number and a technical and application service hotline must be available for any questions or problems that may arise. Mostly both hotlines can be organized or provided by your renal care center. If everything goes well, doctor and patient will only need to see each other at intervals of several weeks for a thorough routine check-up.

“My quality of life is so much better! I wouldn’t want it any other way now.”



Thanks to technical advances, this form of treatment, specifically intended to provide greater autonomy, is suitable for growing numbers of patients — but by no means all of them. Even today, satisfying strict medical criteria is still very important for home hemodialysis: the patient needs to be in a stable state of health, with a well-functioning AV access, and must have the dexterity and technical skills needed to be able to carry out the procedure safely. However, there are always some patients who feel more comfortable with in-center dialysis. It is advisable that patients who dialyze at home have the support of a partner while they undertake hemodialysis in case they need help or in case of an emergency. However, there are always special technical solutions for those who are able to carry out home hemodialysis on their own.

In addition to the personal abilities required, adequate facilities and space for home hemodialysis also have to be available. The house or apartment has to have space to accommodate the dialysis machine and a technical installation for producing ultra-pure water, as well as for the dialysis bed/chair and for storing of the treatment materials.

GETTING EVERY LAST TECHNIQUE RIGHT

Before home hemodialysis starts, patients (together with their dialysis helpers) receive preparation for it in detailed courses and training sessions. These are usually initially held in the center and later on at home. Each point is practiced repeatedly until every last technique is right: from correct handwashing and blood-pressure measurement to drawing up syringes and connecting the tubes. This process can take several weeks or even months.

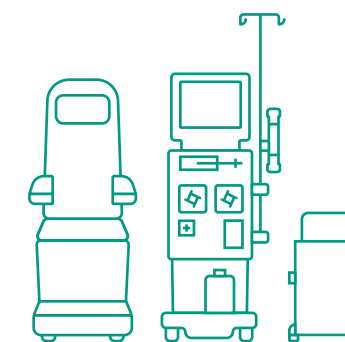
Many patients are particularly apprehensive about puncturing the AV access. But there is hardly any need to worry — as one patient reports who has been carrying out home hemodialysis for several years already. He personally thinks there's less pain when he does it himself than when someone else does it. He no longer has any worries that it might go wrong. Even if there were problems, he thinks the situation would still be manageable for him, and if necessary, he would be able to just disconnect on his own.

Many patients become more motivated with home hemodialysis and treat themselves 6 times a week for 2.5 or 3 hours. In those patients dietary restric-

tions or fluid intake restrictions are mostly no longer required as toxins and fluids are removed daily. Others remain on 3 treatments a day but voluntarily stay longer on the treatment. This can have very good effects on their toxin removal. Both ways are promising for health and well-being.

These are all good arguments — but the responsibilities required for hygiene and precise handling of the syringes remains the same as for in-center dialysis patients. However, most home hemodialysis patients gain more expertise in cannulating their own fistula than a nurse can ever achieve. Possible complications of a fistula are presumably earlier detected if a patient knows that he/she has full responsibility for the fistula. Patients who carry out dialysis at home gradually become more relaxed and unflappable about it, because although dialysis is more complicated than just brushing your teeth or washing your hair, it sooner or later becomes a quite natural part of your everyday routine — along with the freedom that has been regained.

If you're interested in home hemodialysis, talk to your doctor about it. You'll be able to work out together whether it might be a good treatment option for you.



A certain infrastructure is required for providing home hemodialysis treatments. Therefore the option of a home hemodialysis treatment may not be available in all our centers.

A PATIENT'S STORY

Living a healthy, athletic and happy lifestyle despite kidney disease, dialysis, and organ transplantation: Róbert Gelencsér from Hungary describes how it can be done.

To meet Róbert Gelencsér today is to encounter a perfect sportsman — with his broad shoulders, muscular upper arms, and charismatic smile, he's always just on his way to the next training session. Whenever he can, he powers through his favorite discipline — 100-meter or 200-meter sprinting, or the 4 × 100-meter relay. And with tremendous success: in 2019, the Hungarian, born in 1971 in the small town of Pápa, was voted Hungarian para-athlete of the year for the second time. And in his job as a paramedic, which is just as challenging, he also constantly produces top performances and has been voted male paramedic of the year twice as well.

It was never a predictable career by any means. Róbert's story started with a calamity when he was 13. Even then he was already a sports fanatic, but a case of viral tonsillitis that progressed to the kidneys with inflammation of the renal pelvis changed everything for him all at once. Although Róbert was able to leave hospital after two weeks, kidney problems started up again when he developed a cold a few months later and his kidney function deteriorated irreversibly. He managed to fight renal failure successfully again and again during the years that followed. On medical advice, he only ate gluten-free meals, paid attention to his protein intake, and experimented with herbal teas, yoga, and mental control — and with these methods he succeeded in avoiding the need for dialysis for twenty years.

When he received a diagnosis of renal failure in his early 30s, however, even a tough fighter like Róbert fell into a deep depression. "It was a very depressing time. I went through a crisis. No matter what I thought, I never knew what was going to happen next," he recalls. Finally, he decided

on peritoneal dialysis at home, supervised by the B. Braun renal care center in Veszprém in western Hungary. The decisive element for his choice of therapy was the fact that it would enable him to continue with what was most important to him personally: his sports activities and his job.

The fact that peritoneal dialysis was not very widespread at the time did not hold Róbert back from the plan. He received support from the B. Braun team and the medical staff in his center. He particularly appreciated the intensive way they paid attention to his special needs and answered his questions. "I went through the necessary training, and was reassured. And then the treatment started after a month of waiting and getting ready."

Looking back, he still thinks it was exactly the right decision for him. Róbert was able to carry on working, although of course he had to soft-pedal a bit for the peritoneal dialysis to start with. Things became ideal when he was able to go on overnight dialysis. At that time, he recalls, it was enough to send the records of his treatment results to the center once a month. "All in all, I felt completely free."

When he received an offer of kidney transplantation in 2006, Róbert initially shrank from the idea. Everything had already become so routine in his life. Transplantation would mean decisive changes — particularly involving a prolonged break for rehabilitation and training. So, he declined the first kidney and asked for a delay to enable him to prepare himself mentally for the new period in his life.

2019
Róbert Gelencsér
was voted Hungarian
para-athlete of
the year for the
second time.

SOMEONE WHO NEVER GIVES UP!

WHEN
I DO ANY
SPORT, I

FEEL
GOOD



"I knew my life would be different afterwards." To prepare himself for it, Róbert needed more information, and he turned to the Hungarian Organ Transplant Patients Association for details. It took several months for him to finally reconcile himself to kidney transplantation. "I had to accept this, but it was a much better solution than dialysis, as I knew I wouldn't have to go through daily treatment any more and my condition wouldn't get worse." When he was offered another kidney, Róbert was inwardly prepared for it so that the transplantation could be carried out the very next morning.

Although the doctors had predicted he wouldn't be able to do any sports training for six months, Róbert already started on his beloved running as soon

as he was able. From the very start, he was motivated by the idea that through the Hungarian Organ Transplant Patients Association, he might have an opportunity to qualify as a para-athlete internationally.

Today he has a happy and healthy life with his wife and two daughters in his home town of Pápa. Whenever they can, they go hiking or cycling together. He's convinced that his passion for running even helped him recover from the transplantation faster. "Sport maintains our physical and mental balance. When I do any sport, I feel good." Róbert's perseverance and commitment were crowned with success when he was recognized as para-athlete of the year for the second time in 2019. For Róbert, sports are not only a life-

long dream but also the energy source that has helped him overcome all of his difficulties. Asked if he has a special tip for other dialysis patients, Róbert says it would be to cultivate or develop a love for sports and activities. Because it's just extremely important

"to have a strong, robust body to counteract the physical effects of the treatment."



"All in all, I felt completely free."



HOW TO REINFORCE YOUR

TIPS

Personal team

Having chronic kidney disease changes lots of things in life — and the same applies to the people you live with every day. A few easy steps can help ensure your "support team" isn't overstrained or feeling left on their own:

1

Speak to your relatives in detail about your treatments, the medical instructions, and possible effects of your condition in everyday life. For example, if people around you know that tiredness and lack of concentration are potential side effects of the disease, they'll be able to adjust to them better.

2

Having meals together creates special links with family and friends. So, it's absolutely necessary to find a way of enjoying meals together, even with the dietary changes required for your health. Only small adjustments are needed in most cases: for example, using more fresh herbs instead of salt when preparing food. You can order our dialysis recipe book via dialysis@bbraun.com

3

Sometimes it does you good just to be able to talk about things with people who are in a similar situation. Not only for patients, but also for relatives of people with kidney disease, there are self-help groups in many countries nowadays that can provide advice and assistance. Encourage your relatives to make use of these networking services. They will not only be able to get lots of useful information but will also be able to build up a network — for those difficult moments when you and your personal team are needing support.

FAQs

I HAVE A FEW QUESTIONS ABOUT TREATMENT OPTIONS — WHO CAN I ASK?

Your doctor is of course the primary contact for all questions about your personal treatment options. In addition, you can also get further information (e.g., from your health-insurance company) about patient organizations or networks, which often offer advice or talks and enable you to make contact with other patients who are affected. The Internet also has numerous forums in which patients with renal insufficiency can swap notes about everything to do with the disease. Certified patient mentors are now available in many renal care centers — other patients who have been specifically trained in counseling who can combine well-founded specialist knowledge with personal experience.

WHAT DOES "PATIENT EMPOWERMENT" MEAN?

Scientific studies have shown that medical treatments are particularly successful when patients have a good understanding of their condition, are included in medical decision-making, and are able to contribute actively to their own health. An approach that involves providing patients with various information services and corresponding forms of treatment is called "patient empowerment." The aim of this approach, which has now been growing in importance for several years, is to give patients more independence, a greater say in treatment, and more health competence.

HOW CAN I PROTECT MY CENTRAL VENOUS CATHETER (CVC)?

A central venous catheter can be used either as a temporary or permanent access route for dialysis instead of an AV fistula. Sometimes it is the only option, but it is often used only until the occluded fistula is repaired or a new AVF fistula can be created. To make sure the risk of infection stays as low as possible, however, special precautions are necessary. To protect your CVC, the dressing must always be close-fitting, attached, and must remain dry (important during washing). It is possible to shower with a CVC by taking special precautions using a waterproof cover over the CVC dressing. Your doctor will be able to give you tips for healthy ways of washing. Please also let him or her know at once if you notice any signs of inflammation, such as fever or swelling and pain on your skin.

WHY IS FLU VACCINATION SO IMPORTANT?

In patients with chronic kidney disease, the performance of the immune system is impaired and the immune medication often needed is also less effective. That's why the course of a flu infection is mostly much more severe in dialysis patients. Moreover, patients with kidney disease have less protection against a lot of microorganisms, and they are at greater risk of developing pneumonia after an influenza virus infection. However, a simple annual vaccination in October or November can effectively counter the danger.

Magical DOWN UNDER

LINDFIELD



Encountering kangaroos on unspoiled beaches, roaming through the rainforest, and diving into a vibrant metropolis of 5 million people — you can do it all from Lindfield, a green suburb of Sydney, where holiday dialysis can be ideally combined with discovering all the diversity of south-eastern Australia.

South-eastern Australia is a travel destination that's full of contrasts. Here in the state of New South Wales, a whole string of fabulous beaches meets up with steep mountain landscapes, the dusty outback bursting with energy, charming hilly vineyards, pristine rain forest, and one of the world's most fascinating metropolises: Sydney.

Lindfield lies to the north-west of this hyper-urban population center — a green suburb with historic villas and bungalows in the Californian style. The superbly equipped center for your vacation dialysis is located directly on the central Pacific Highway. From Lindfield, you can reach Sydney city center in less than 30 minutes — for example with the North Shore railroad, which links the suburb with the city center at ten-minute intervals.

In contrast to quiet and suburban Lindfield — 13 kilometers from Sydney's city center and already on the edge of the Australian bush country on the outskirts — the neighboring district of Chatswood is already one of the liveliest commercial districts in the city, with countless shops, cultural and dining facilities, and a wide choice of hotels.

From both Lindfield and Chatswood, all of the city's tourist attractions can be reached very quickly — including of course the world-famous Sydney Harbour Bridge and the city's architecturally unique Opera House. That means that if you go to dialysis in the morning, you'll have time in the afternoon for a tour through Sydney's beautiful harbor, with a stroll through the lively shopping center of Darling Harbour, an excursion to the surfing mecca of Bondi Beach, or a visit to Sydney Tower, with its spectacular view of the city.



On the other hand, you might want to opt for the alternative program and start exploring the country on the way out of town. No problem; there are lots of hiking trails into the nearby national parks that start directly from Lindfield. You could also go on more extended excursions — for example, to the steep, majestic Blue Mountains or the fascinating Australian outback. And you're sure to want to visit the unspoiled beaches along the east coast, as well as Hunter Valley, Australia's oldest wine-growing region.

Whether it's a city trip or a close encounter with kangaroos, duckbilled platypuses and wombats: lots of destinations for your personal dream trip can be effortlessly reached from the outskirts of Sydney. And when you return to your hotel in Chatswood after an outing, you'll be welcomed not only by the aromas wafting from the numerous Asian restaurants that give the district its special character, but also the magic of a metropolis that is always cheerful, multicultural, and fantastically relaxed. No wonder so many travelers fall in love with the city so much, they say: "Sydney, I'll be back!" Will the same happen to you?

TOURIST SEASON

Sydney and New South Wales have a moderate climate all year round. Between October and April, temperatures are a warm and summery 20–30 degrees Celsius, while in the winter months from June to August it's around 14–20 degrees Celsius. High season in Australia is in December and January. Lots of Australians go on vacation in their own country during this period — so hotels, rental cars, and restaurants tend to be already well booked up. Ideally, you should travel in low season or plan your trip well ahead of time.

Sydney, I'll be back!

WORTH KNOWING

Arriving: Sydney's Kingsford Smith International Airport is around 10 kilometers south of the city center. Lots of hotels provide a shuttle service. You can also easily reach Lindfield and Chatswood using public transport: take the train to the main station and transfer to the North Shore line on platform 16. The journey time is around 45 minutes.

FURTHER INFORMATION

For more information about Chatswood (including hotels),

VISIT: <http://www.visitchatswood.com>

For more information about Sydney and New South Wales,

VISIT: www.australia.com

Lindfield Renal Care Center
280–286 Pacific Highway
Lindfield, NSW 2070, Australia

VISIT: www.bbraun.com/en/patients/renal-care-for-patients/renal-care-centers/australia/lindfield--nsw.html

For your personal travel and appointment planning, you can contact the center at:

Tel.: +61 2 9415 8800

E-mail: lindfield-reception.au@bbraun.com

RECIPE

CHICKEN

SWEET AND SOUR

Serves 4

- 4 chicken breasts, skin still on or skinless
- 8 TBSP of olive oil
- 2–4 sprigs of thyme
- 2 sprigs of rosemary
- 1 chili pepper, cut into 4 longitudinal pieces, seeds removed and chopped into small cubes
- 1 chopped garlic clove
- Zest of a whole lemon
- 1 bell pepper, cut into cubes
- 1 peeled carrot, cut into cubes
- 1 TSP of brown sugar
- 2 handfuls of mung beans
- 2 TBSP pineapple chunks (canned)
- 2 TBSP tomato paste (canned)
- ½ TSP of peeled ginger root cut into tiny cubes
- A few sprigs of cilantro
- ½ TSP of chili peppers, finely cubed
- 1 TBSP of green chili sauce
- 1 TBSP of soy sauce
- 200 g black and white rice

Rice

Boil the rice in plenty of water and serve as a side.

Preparing the chicken breasts

Marinate the chicken breasts in 6 tablespoons of olive oil, 2 to 4 sprigs of thyme, 2 medium-sized sprigs of rosemary, chili, garlic, and lemon zest in the fridge for half an hour. Remove and sear in a hot pan until golden brown with the skin side down first (if any). To cook through, place in the oven for 20 to 25 minutes at 160 degrees C.

Sweet and sour vegetables

While the chicken is in the oven, cook the bell peppers and carrot cubes in plenty of water until soft. Caramelize the sugar in a large, deep pan or wok. Add 2 tablespoons of olive oil, mung beans, the pineapple chunks, tomato paste, ginger, cilantro, chili and chili sauce and swirl the pan around to blend for 2 minutes or so. If desired, season to taste with soy sauce.

Asian dishes, e.g. preparations with rice, are highly recommended additions to your diet in general, especially if you are going out for dinner. The chicken is the source of protein in this dish. Bean sprouts contain considerably less potassium and phosphates than dried beans and also deliver lots of vitamins. Tomatoes are not a key ingredient, they just add flavor to the sauce.



Nutrition value (All nutritional information per serving. This corresponds to 1/4 of the total recipe.)								
Energy	Carbohydrates	BE	Protein	Fat	Potassium	Phosphate	Sodium	Water
557 kcal	45 g	3.7	31 g	28 g	530 mg	327 mg	97 mg	282 ml

These nutritional values represent average figures, which may differ in certain cases. They should be used only as a guide and cannot replace a consultation with your doctor or nutritionist.

Qi Gong is the name for the Chinese art of slow movements. The aim is to achieve harmony between body and mind. The gentle and effective mixture of physical exercises and meditation can be carried out while lying down, sitting, standing, or walking — so it's also ideal for people with physical restrictions, and it can even be practiced during dialysis.

You've probably already seen them in the park: groups of people concentrating on doing flowing, enchanted-looking physical exercises together, as if in slow motion. The phenomenon has been part of everyday life in China for centuries, but it has been growing increasingly popular in more and more places all over the world in recent years. The healthy effects of the exercises — which have poetic names like "frolic of the five animals," "eight brocades," or "white crane spreads its wings" — speak for themselves. For long-lasting effects on health, experts recommend 10–20 minutes of Qi Gong every day. The result: many physical symptoms disappear, the mind becomes clearer, emotions are calmer, and the body becomes stronger and more mobile.

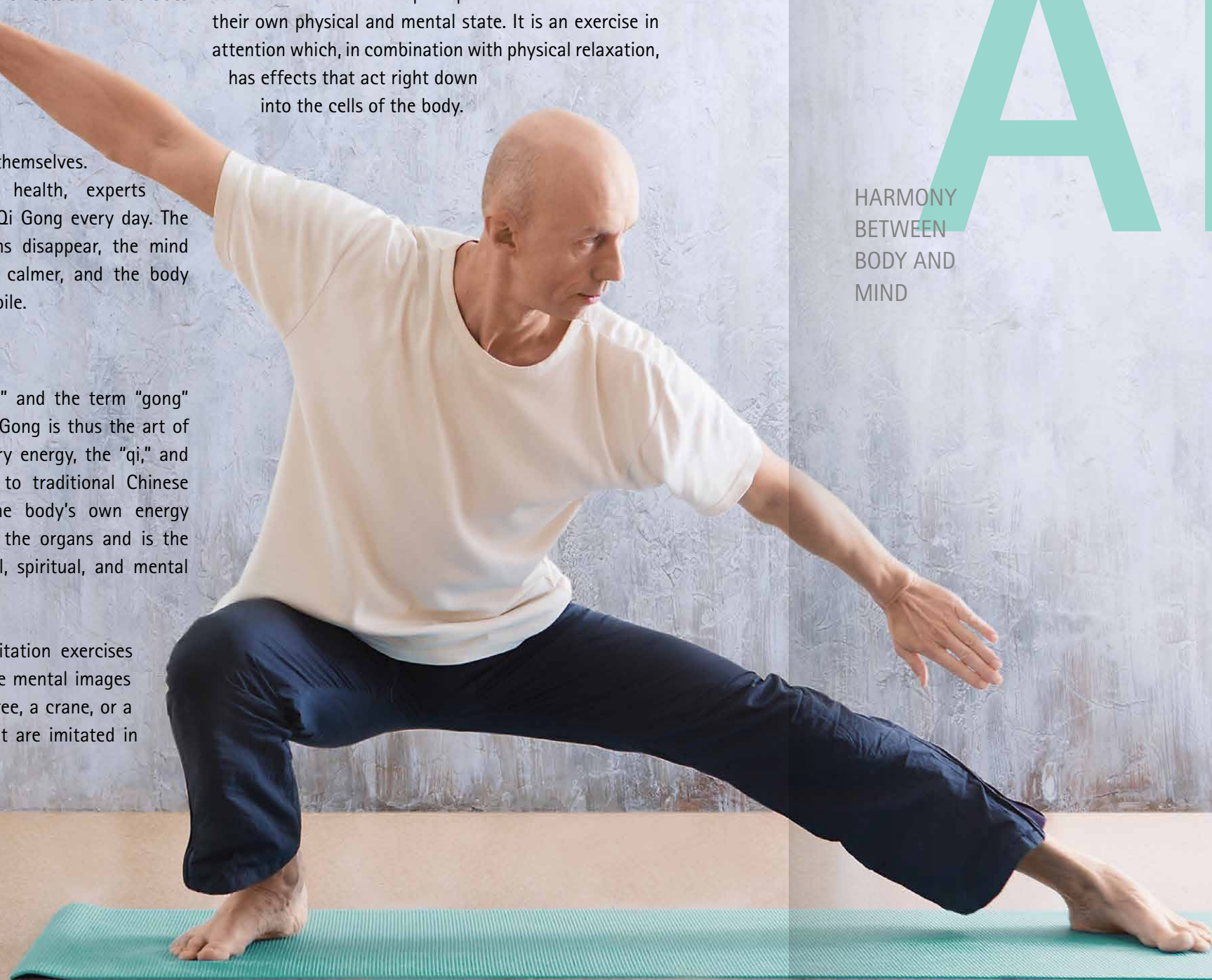
WHAT DOES QI GONG MEAN?

In Chinese, "qi" means "energy," and the term "gong" means "persistent exercise." Qi Gong is thus the art of increasing the body's elementary energy, the "qi," and causing it to flow. According to traditional Chinese medicine, it flows through the body's own energy pathways (called meridians) to the organs and is the basic force behind our physical, spiritual, and mental health.

All of the movement and meditation exercises in Qi Gong are linked to positive mental images drawn from nature, such as a tree, a crane, or a bear, whose forms of movement are imitated in

the exercise: a harmonious combination of attention, breathing, and movement.

With the help of visualization aids, one's mental focus is guided to physical processes when the exercises are being practiced. Those who practice Qi Gong can thus enhance their self-perception and their sense of their own physical and mental state. It is an exercise in attention which, in combination with physical relaxation, has effects that act right down into the cells of the body.



HARMONY
BETWEEN
BODY AND
MIND

Much more
than just

RELAXATION

LEARNING QI GONG:

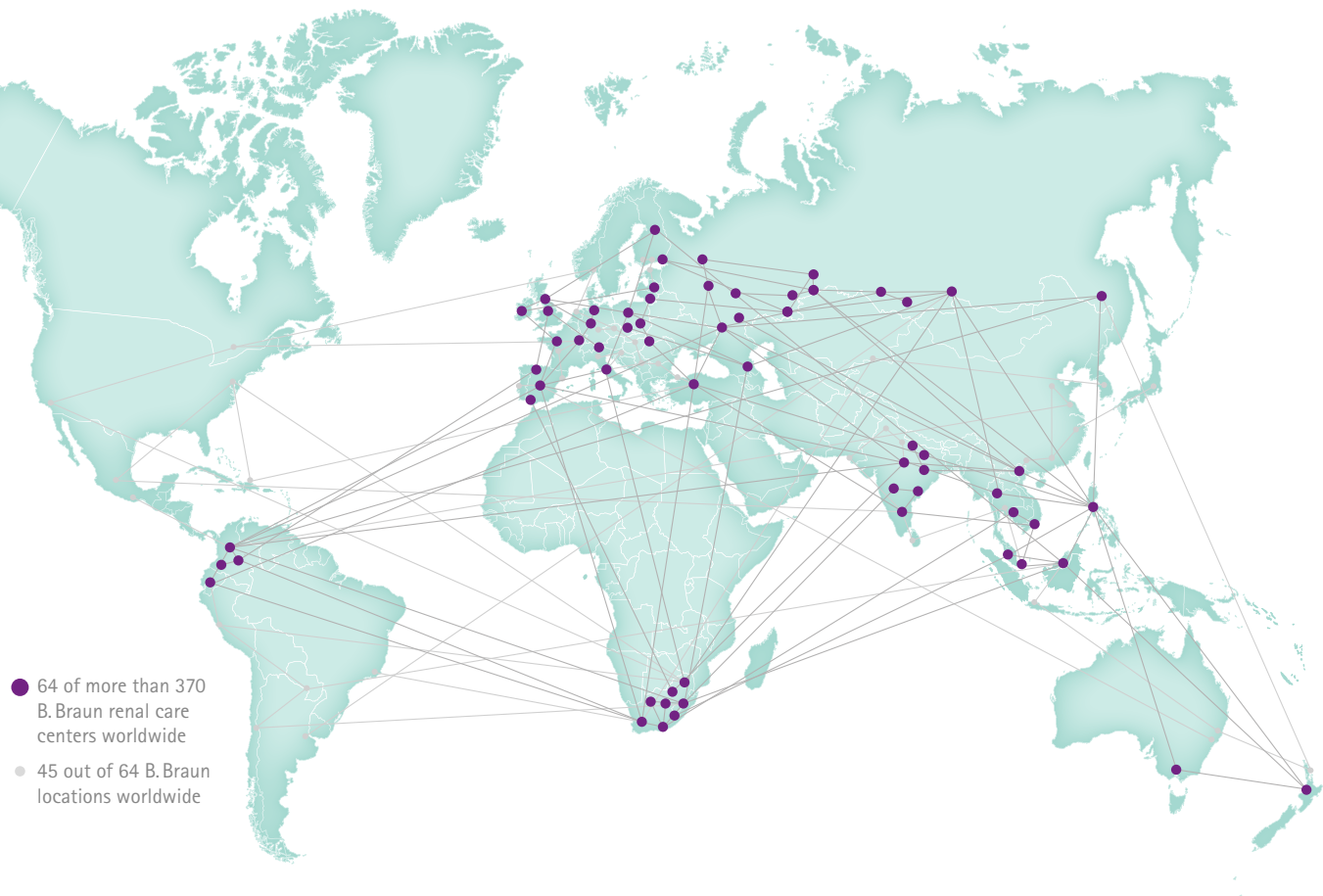
There are a large number of different Qi Gong exercises from many varied traditions, with varying levels of physical challenge. However, the movements — which are always gentle, flexible, slow, and unforced — are easy for most people to imitate. Older people or those with physical restrictions are also able to practice Qi Gong very well — for example, while sitting, or what is known as "motionless Qi Gong," which dispenses with external movements completely. Some exercises can thus be practiced during hemodialysis without any problems.

For people wanting to learn Qi Gong, the best plan is to get advice and training in a course given by a Qi Gong master. Although numerous video introductions are now available on the Internet, it's better to look for an experienced teacher to start with so that you can learn the exercises precisely and adapt them optimally to your own personal needs and physical limitations.

You can find
useful information
for your
health & fitness
at our website,
www.bbraun-dialysis.com.

A NETWORK OF COMPETENCE

Exploring the world with B. Braun



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