

share *for* care

A PATIENT'S STORY

Darren Cawley, a runner from Ireland, refuses to let kidney disease slow him down

RECIPE

Beef steak with sour cream and fried onions

HEALTHY LIFESTYLE

Skin care and dialysis: Which kinds of products are right for me?

TRAVEL STORY

NENZING – AUSTRIA

A year-round alpine wonderland with all the amenities



Dear readers,

What's the best way of making treatment for kidney disease as successful as it can be? And how can you get beyond the challenges the disease brings with it, and still have a good life in spite of it? It's questions like these that dialysis patients all over the world are asking. In this issue, we'd like to introduce you to Darren Cawley, whose story strikingly illustrates how you can still have a good life despite kidney failure. The friendly Irishman's inexhaustible fighting spirit is just amazing and inspiring. Darren had to get through several difficult years before things took a turn for the better and he received a new kidney. Today he's able to live without dialysis in a way he hardly dared hope for.

Winter's just round the corner now and there's no denying that it comes with a few problems. But with the tips in this issue, you can relax and make the best of the chilly season. The most important thing is: take good care of yourself! And that starts with the skin, which can get rough and dry from the air in centrally heated rooms and from being exposed to the cold. Taking a bit more care with your skin can work miracles. Plus, experience shows that a hearty meal is good for you at this time of year. Being a dialysis patient doesn't mean you can't enjoy your food! A tasty steak with fried onions makes a great meal for a big appetite. Try out the recipe in this issue and send us a photo of how it turns out, to: dialysis@bbraun.com.

The travel story in this issue again shows how life can still provide all sorts of new and exciting moments in store for you. For example: have you ever visited Heaven on Earth? It's a place that does actually exist (Nenzinger Himmel), in the village of Nenzing in Austria. You can take all the time you need and discover this splendidly named idyllic plateau on foot – after enjoying a view of the Alps during your dialysis treatment. Winter could hardly be any more beautiful!

We hope we've been able to put together a lot of interesting articles for you in this new edition of *share for care*. What's really important to us is helping you see what an important part you yourself can play in making your treatment successful. The same also applies to the important subject of weight management, which many patients find difficult. That's why we've focused on it as a special topic this time, with lots of practical and valuable information for your daily routine. Our aim is to provide you with clear and useful information about every aspect of successful therapy and a good quality of life while facing the challenges of kidney failure. What would help us achieve this goal more than anything else is for readers to get involved. So we'd be delighted to receive any questions, comments, and ideas from you!

Hoping you enjoy the new issue!

Your editorial team



Christopher Boeffel



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share for care



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A PATIENT'S STORY

Find out how Darren Cawley sets the pace for dialysis patients

Great prospects for curing HEPATITIS C



continually adjusted. The new anticoagulants, known as direct oral anticoagulants (DOACs), instead act directly against specific coagulation factors. They are available under generic names such as dabigatran, rivaroxaban, and apixaban. As they are easy to use, many physicians now prefer them, particularly because they make constant coagulation check-ups unnecessary. The doctor treating you will know which drug is suitable in your own case.

STRICT BLOOD PRESSURE CONTROL

can save lives

Until only a few years ago, chronic infection with hepatitis C virus was often in the long term fatal. But thanks to effective drugs, nearly everyone with the infection can now be completely cured. Although the treatment is currently still expensive, the fight against hepatitis C has been one of the biggest medical success stories in recent years. Thanks to modern protective measures, the risk of infection during dialysis is now also negligible. But it's still important to detect the disease as early as possible – so your doctor tests you for hepatitis C antibodies every 6–12 months. Preventive measures like this mean that in the not too distant future, the goal of medical research might even be reached: eradicating hepatitis C completely.

Blood pressure that is either too low or too high means considerable health risks for patients with chronic kidney diseases – so the issue of the optimal blood-pressure level has become a much-debated topic among medical specialists. But according to a clinical study at the University of California, the benefits of strictly avoiding high blood pressure seem to be more important in the population they investigated. The researchers recommend keeping systolic blood pressure down to about 120 mmHg. This could protect many patients with chronic kidney disease, esp. by slowing down the development of cardiovascular conditions at an early age.

NEW ANTICOAGULANTS

are the drug of choice

in many cases

During dialysis treatment, the blood coagulation process has to be slowed down in order to avoid the risk of blood clots and thromboses. Until recently, the only orally available drugs to do this were ones that acted indirectly, like phenprocoumon (e. g. Marcumar) or warfain. These agents reliably block the anticoagulant action of vitamin K, but their dosage has to be



NEWS



TELEMEDICINE

improves treatment quality

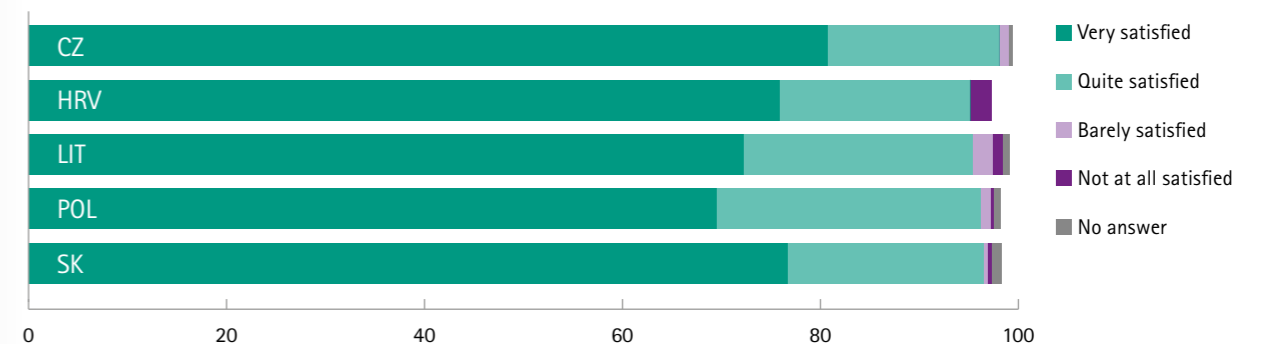
Dialysis patients who record their vital data using electronic devices and share them with their doctors online evidently do better than others. A study in clinics run by Renal Ventures Management in Dallas provided one group of patients with the devices for a period of 4 months. Every day, the patients recorded their blood pressure, pulse and blood sugar value, among other data, and they completed a health education program on their tablet computers. In comparison with a control group, the patients who received telemedicine support were better at keeping their dialysis appointments and also had noticeably fewer medical complications.

PATIENT SATISFACTION SURVEY

How satisfied are you with your renal care center in general?

It is important to us to ensure that we provide a responsive and comfortable environment for our patients. In 2006, we began conducting a patient satisfaction survey to learn what is important to our patients and how we can meet their needs. Since then, we have conducted this survey each year to enable we are continually improving our services.

This provides every patient with the opportunity to give us anonymous feedback on their experience. We use this open communication to improve our care and service level at renal care centers and across the whole organization. In 2016, we were able to collect feedback from almost 15,000 patients representing 22 countries worldwide.



THE PATH TO NUTRITIONAL

BALANCE

KEEPING TRACK OF FLUIDS AND CALORIE INTAKE



What most people usually think about in connection with weight problems is the effort to get rid of excess weight. Extra pounds on the scales are also an important topic for patients with kidney failure – but for them, it's not just about keeping slim. Weight problems are often also linked to health problems, which are different from those in people with healthy kidneys. **Much more important than your ideal weight here is what's called dry weight: the weight at which a dialysis patient feels comfortable and well.**

What does this mean to me? The dialysis-dependent body weight is made up of water, fat, and what scientist generally call cell mass, which contains mostly proteins. The weight reduction that takes place during dialysis is based on removing water from the body's cells (intracellular) and the space between the cells (extracellular). Weight loss that is not dialysis-dependent could be usu-

ally a result of malnutrition.

It's often due to reducing weight – either deliberately or unintentionally – without advice from your care team: using dietary supplements with bulkage, reducing food intake with "eat half as



much" diets, periodic fasting, carbohydrate-free diets, etc. These mean that not enough protein and energy are supplied, leading to a loss of fatty tissue and muscle mass. **These approaches are already problematic even in people who have healthy kidneys – and in dialysis patients they can be dangerous. Before you change your diet discuss this with your care team.**

WEIGHT CONTROL

The body's weight varies from day to day, for understandable reasons: we don't eat the same



amount of food every day, and of course we also use up different amounts of energy depending on the various things we do. The intake and excretion of liquids beside bowel movements play a major part in weight variations. So it's not unusual to see variations of more than a couple of kilogram in one day, particularly in dialysis patients. Differences in weight between two dialysis sessions will be caused mainly by fluid gain or loss, not loss of muscle mass or fatty tissue. These changes aren't prevented by dieting, but rather by keeping strictly to the amount of liquid the physician recommends. If you notice a gradual increase in your pre-dialysis weight, even though you are keeping strictly to your

recommended drinking quantity, it could be usually a sign that the kidneys' ability to excrete water is declining. Increases in weight that are only noticed sporadically may suggest that too much liquid is being taken in. Water retention in the legs and feet is a clear sign that the body is holding back water – e.g., because it is no longer able to excrete it due to renal failure. Without care water retention can lead to high blood pressure, long-term impairment of blood vessels, or even heart damage or pulmonary edema.

Errors in recording a patient's weight are often caused not by the weighing process itself, but rather by missing the



fact that something has changed for the dialysis patient. For example, the patient may be wearing a plaster cast after an accident, may have undergone an amputation, or depending on the time of year may be wearing heavy shoes.

PAYING ATTENTION TO THE IDEAL FLUID INTAKE

However, patients who hold to the amount of fluid intake that the doctor recommends can keep the risk of water retention well under control, as long as they don't lose fat or muscle mass without noticing it. Ideally, the intake and excretion of water should always be in balance. The average daily excretion of urine, if apparent, should be measured on a regular basis.

That means: you may only drink as much as your body can also excrete (rule of thumb: daily amount of urine excreted

+ around 1 pint (500 mL) = recommended amount of fluid intake). Every now and then (around every two weeks), you should measure the amount of urine you pass daily, and make a note of it. It's also important here to pay attention to hidden amounts of fluid – in fruit, soup, and yoghurt, for example. These food-stuffs consist largely of water, so they have to be included when you calculate your liquid budget. Any loss of water during diarrhea should also not be overlooked here. Stepping onto the scales before and after dialysis is enough. The nursing staff will take account of the fact that you may be wearing different clothes, or that your weight is different from the previous appointment because it's a different time of day. However, if the weight variation between two dialysis appointments is significant, some thought needs to be given to what the cause might be. The excess water also needs to be removed during dialysis.

The general rule is: in a dialysis patient, weight losses are a clear warning signal; weight increases are much less of a problem. Increases are often a sign that the patient is well.

WHAT DOES DRY WEIGHT MEAN?

The target value for the nephrologist is always the "dry weight" – i.e., your body weight immediately after dialysis treatment. Dry weight is used to try to calculate the weight a patient would have if he or she were healthy and able to completely eliminate excess water. It is not a constant weight. It may increase when you eat well and may decrease if you ingest less energy (fewer calories) than you normally do. In practical terms, the nephrologist calculates dry weight for example by weighing you, measuring your blood pressure, and other methods. Both the patient and the physician who is providing treatment can recognize a successful dialysis by the fact that the

patient feels well and afterwards has blood pressure that is neither too high nor too low. If you suffer from dizziness, cramp in the calf muscles, or low blood pressure after dialysis, it's possible that too much water has been removed. Speak to your physician about it, so that the dry weight value used for the next dialysis can be increased accordingly.

WHEN YOUR WEIGHT FALLS

It often happens that dialysis patients suffer from a lack of appetite. This should never be regarded as a welcome way of reaching your own personal ideal weight. Instead, what's important is to maintain your weight and ensure a high-calorie, low-fluid diet. This is best done

with small, frequent meals that are prepared and garnished as tastily as possible. So spoil yourself! Doing some light exercise and taking a walk in the fresh air can also give you a good appetite and help build up and maintain muscle. If you have longer-lasting nausea or loss of appetite, you should speak to your physician.

KEEPING YOUR THIRST UNDER CONTROL – THIS IS HOW!

RECOMMENDED

- Spread drinks across the whole day
- Drink slowly
- Use small cups with known capacity
- Include hidden liquid in soups, creams, sauces, and yoghurt in calculations
- Use fresh herbs instead of salt when cooking
- Suck sour balls, lemon slices, and ice cubes (but count the liquid)
- For a dry mouth, brush your teeth or use a mouth rinse

AVOID

- Salt-containing and very spicy foods
- Ready-made meals, ketchup, and pickled foods
- Adding salt at the table
- Hot drinks





THE FASTEST SICK PERSON IN EUROPE!

Darren Cawley (38) from Ireland was dreaming about becoming a professional sportsman when he was diagnosed with renal failure at the age of 20. It was a terrible blow for him – but it was also the start of a fascinating journey of discovery, revealing new areas of life and unsuspected talents.

Darren remembers he used to be very shy – a quiet boy from an Irish village. “If there was one thing I really hated, it was talking.” Maybe because his four sisters hardly ever let him get a word in at home, Darren preferred going out to play with a ball instead. He enjoyed just about every kind of sport: football, rugby, handball, squash, boxing

– and he was good at all of them without much effort. So when he finished school, it was logical for him to do sports studies at the University of Bedfordshire, where he started out with tremendous enthusiasm.

One day, the young Irishman had to go to his doctor because of eye problems. “I thought I needed glasses.” Instead, the doctor started investigating his blood pressure. Shortly after came the diagnosis: kidney failure. To begin with, he had no idea what that meant, Darren recalls. An emotional rollercoaster started. Only just recently healthy and fit, and now chronically ill. But then after 6 months adjusting to living with dialysis, his life jumped onto a new track once again: Darren unexpectedly

Darren



Cawley,

received a donor kidney! Shortly after the successful transplantation, he was able to travel to the World Transplant Games in Japan, as a member of the Irish national team. An experience that changed his life – and not only because of the two bronze medals that he brought home. “It was just tremendous, the world that opened up for me there. I was able to represent my country internationally and I met people from all over the world, people who were doing incredible things physically – all sorts of things I would never have experienced as a ‘healthy’ sports student!”

When Darren lost his new kidney two years later due to an infection, he had just won the gold medal for 400 meters at the European Transplant and

Darren Cawley, who gave a highly motivating speech at our B. Braun plant in Melsungen, recently became a father for the first time. We revisit Darren and his inspiring story for patients with kidney failure and equally the staff who work hard to ensure the good health of so many others with a similar illness.

Dialysis Games. “You could say I was the fastest sick person in Europe,” he laughs. His easy sense of humor hides how hard the blow must have been for him. He now had to go for dialysis every other day again, not knowing whether he would ever receive another donor organ.

“It was difficult,” he remembers. “But once I actually accepted the disease as being part of me, it got easier. Acceptance is the key. Once you’ve managed that, it’s a matter of finding out together with the doctors what the best way is of getting to a body that I’ll feel well in.” Darren decided to make use of every moment of his time: he used the dialysis hours to study books and communicate all over the world in various communities and forums, and his active hours for sports training, along with as many trips as he could possibly manage. His goal was always: to challenge his body and overcome barriers. He was helped by a firm conviction that he would always be supported by rapid progress in medical developments. At the European Transplant and Dialysis Games

in Germany in 2008, Darren won all the races at 100, 200, and 400 meters. Overall, he can now look back on 11 years of dialysis and more than 1,700 hospital stays.

The likeable Irishman has long since also discovered a new passion: public speaking. “I love getting people enthusiastic and making them laugh.” He started by giving talks in schools about living with kidney failure. In the meantime, he now travels from conference to conference as an internationally sought-after speaker. He has even inspired the members of the European Parliament with a speech about chronic diseases from the patient’s point of view. Darren is convinced you can live a good life with renal insufficiency. And he had another stroke of luck just recently – he received a new kidney and he’s hoping he will now always be able to live without dialysis. He has become a father as well. Congratulations! Darren Cawley lives with his family near Westport in Ireland.

VISIT:

www.darrencawley.com

ENJOYING THE WINTER

Frost, short days and not much sunshine: facing up to the cold season is a fresh challenge for us every year. But with the right activities, you can do a lot for your own personal well-being. Here are a few tips.

1 Gentle stamina training keeps the cold away

Exercising during the winter has at least one clear advantage: less sweat. Take your body up to a comfortable working temperature with a round of Nordic walking or cross-country skiing. If you've got the right clothing and you get enough exercise, you can be sure you won't get cold. But always make sure your shunt is well protected. Special cuffs are available at your care center.

2 Light will put you in a good mood

Sunshine and daylight are particularly valuable in the winter and help keep the winter blues away. Fix your appointments so that you have time to go for a walk as often as possible during the brighter hours.

3 Extreme cold – best avoided

Very low minus temperatures are not advisable for dialysis patients. On particularly nasty days, it's a good idea to visit the fitness center – or exercise at home. What about an impromptu tea-dance in your own living room?

4 Wintertime – wellness time

Use the quiet season to give yourself a special treat. Things like a gentle massage or relaxation courses with yoga or autogenic training are ideal. A moderate sauna is also possible, as long as it doesn't make you too thirsty. In that case, swimming in a warm pool would be better – provided your doctor gives you the OK for it.

FAQs

I want to avoid long travel times. Does it make any difference if I go for dialysis twice a week for six hours or three times a week for four hours?

Yes. Even though it might be more practical, it's not possible to concentrate the dialysis into two days per week. This is because the toxins in your blood start going up again immediately after the treatment. Two dialysis-free days are possible in many cases, but it should never be more. This is why the Nephrology societies recommend a dialysis frequency of at least three treatments per week.

Unlike other dialysis patients, I pass quite normal amounts of urine. Do I actually have kidney failure at all?

This is not an unusual experience. In many patients with renal insufficiency, passing water still works quite well, particularly when they are new to dialysis. But the amount of urine alone does not give any reliable information about kidney function. The decisive part is whether your kidneys are still able to excrete toxins, or need help from dialysis to do this.

I started dialysis 6 months ago and I now feel much better. Do I still need to have the treatment?

In general, many patients feel better after starting dialysis. This is because far fewer toxins are present, on the one hand. In addition, dialysis removes excess salt and water, particularly at the start of treatment. All of this makes the body feel better – but it can only last if you continue with dialysis.

Why do I have to wait for so long for the needle site to stop bleeding after the dialysis session?

It's quite normal for the end of the dialysis session to take a little time. But if you have a feeling it's taking unusually long, you should speak to your doctor. It's possible that something might be wrong with your blood clotting, or that the heparin dosage you receive during dialysis needs to be readjusted.

AN ALPINE PARADISE AWAITS YOU IN NENZING

Holidays in Austria's Vorarlberg

Located in western Austria, Nenzing lies at 1,370 meters above sea level. Summer or winter, this beautiful village has it all.



Not every town can claim to offer paradise on earth. But Nenzing can. At an altitude of 1,370 meters (5,000 feet) lies the mountain village with the lovely name "Nenzinger Himmel" (Nenzing Heaven). Meadows, cows, and rustic mountain huts as far as the eye can see. On the sunny high plateau, time seems to stand still — partly because there are no cars to disturb the peace and quiet. But fortunately that doesn't mean you have to walk the 16-kilometer distance (10 miles) from Nenzing. There are regular shuttle buses and taxis to take walkers to "heaven" and back again.

Nenzing is located in the state of Vorarlberg in the west of Austria. Unlike the nature reserve, the town itself is only at an altitude of around 500 meters, but with its railway station and motorway exit it has superb infrastructure links — and since 2009, it has also had an ultra-modern renal care center.

During the treatment, the center's guests can look out on Alpine panoramas in several directions. Only a few yards away from the town center, the renal care center has fourteen modern treatment places, all equipped with TVs. A physician and two nurses are always present and a nephrologist is also on site once a week. The town is an ideal starting-point for all sorts of activities. It's not only hiking and skiing that are available — the town also has attractions for friends of the arts. Schwarzenberg and Hohenems, where the world's largest Schubert festival, the "Schubertiade," is held every year, are only 50 km (30 miles) away. It's also just a stone's throw from Bregenz, with its festival and the legendary opera performances on Lake Constance.

But you also shouldn't miss other sights nearby — Feldkirch, for example, founded in Roman times, or the medieval Alpine village of Bludenz. And in only half an hour you can be in the miniature state of Liechtenstein, where even today there's a genuine prince in residence in Vaduz, the country's capital!

For the winter: recommended skiing areas (accessible by car in less than 45 minutes): Arlberg, Montafon, Brandnertal, Damüls.



Useful facts

Travel: you can reach Nenzing on the Rheintal motorway, the A14 (Nenzing exit). The nearest international airports are Innsbruck (130 km, 80 miles) and Zurich (150 km, 93 miles).

Further information about the vacation area is available at:

www.nenzing-gurtis.at
www.vorarlberg-alpenregion.at
www.vorarlberg.travel



INFORMATION

Renal care center address: Dialysestation Nenzing Bundesstrasse 47, 6710 Nenzing (Austria)
 For your personal travel and appointment plan, please contact Mr. Florian Neyer at:
Phone: +43 5525 63003 · **E-mail:** ferientialyse@dialysenenzing.at · www.dialysenenzing.at



BEEF STEAK

WITH FRIED ONIONS AND PEPPERED SOUR CREAM

This high-protein, low-carb recipe is another example of just how good a dialysis diet can be.



To make the beef steak

In a bowl, mix together the ground beef, egg, softened bun and mustard. Season with the sugar, cayenne, and black pepper to taste as well as a pinch of salt. Use a palm sized amount of the mixture to form burger patties. Sear the burgers in a pan until well done.

And the sides

Cut the brown onion into thin rings, dredge in flour and fry in oil until crispy. Plate like a burger on the rustic bread. If you wish, garnish with celery leaves.



The peppered sour cream

Blend the sour cream or creme fraiche with the green pepper, brown sugar and chives and place in the fridge for 20 minutes.



RECIPE

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
577 kcal	32 g	2.7	34 g	35 g	422 mg	308 mg	144 mg	197 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.

SERVES 4

- 480 g ground beef
- 1 egg
- 1/2 stale bun soaked and pressed dry
- 1 TSP of mustard
- 1 pinch of sugar
- 1 pinch of cayenne pepper
- Freshly ground black pepper
- 1 pinch of salt
- 150 g sour cream
- 1 TSP of green pepper corns
- 1/2 TSP of brown sugar
- 2 TSP of chives
- 1 large brown onion
- 4 slices of rustic bread

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

Balm for the skin



Lots of dialysis patients are quite familiar with it: itching and an unpleasant tense feeling due to dry skin. No wonder – as the body's largest organ, the skin has a lot to cope with in kidney disease. But with the right care, you can give your skin some help and promote your health as well at the same time.

Especially in the winter, it's important to treat your skin well, as it tends to dry out even more than usual. It is best to use lotions that contain both lipids and moisturizers. If possible, you should avoid heavily scented lotions, and the best time to apply the cream is when the skin is still slightly moist after washing and able to absorb the lotion easily.

You should also use mild products for washing as well. Use moisturizing soap-free cleansing products to protect the natural acidity of your skin that is a protective barrier. Water that's either too cold or too warm is also not good for it. Lukewarm water at a comfortable temperature not only feels good, it also causes your skin the least stress. By the way: stress and anxiety are also generally bad for your skin. Allow yourself some active relaxation – with yoga or autogenic training, for example. Try to ensure a home environment that is as quiet and cosy as possible and wear comfortable clothing made of skin-friendly cotton. You should also avoid dust and dust mites as much as possible. Hot drinks and highly seasoned food also irritate the skin needlessly. But moderate sunbathing, UV phototherapy and gentle brush massages can be recommended.

Unfortunately, there is still no cure-all available to prevent itching. So you should experiment to find out which methods are particularly helpful for you. If you have severe and unclear symptoms, it's always worth visiting your family doctor. Because behind the symptoms there's often a clearly diagnosable skin disease that can usually be easily treated.

Why do dialysis patients often have skin problems?
Kidney insufficiency means that urea and residual toxins are deposited in the skin, leading to dryness and flaking. The balance between lipids and moisture is disturbed. Insufficient dialysis and certain drugs can also cause skin problems. Nutrition influences skin well-being furthermore. The best thing is to discuss it with your doctor.

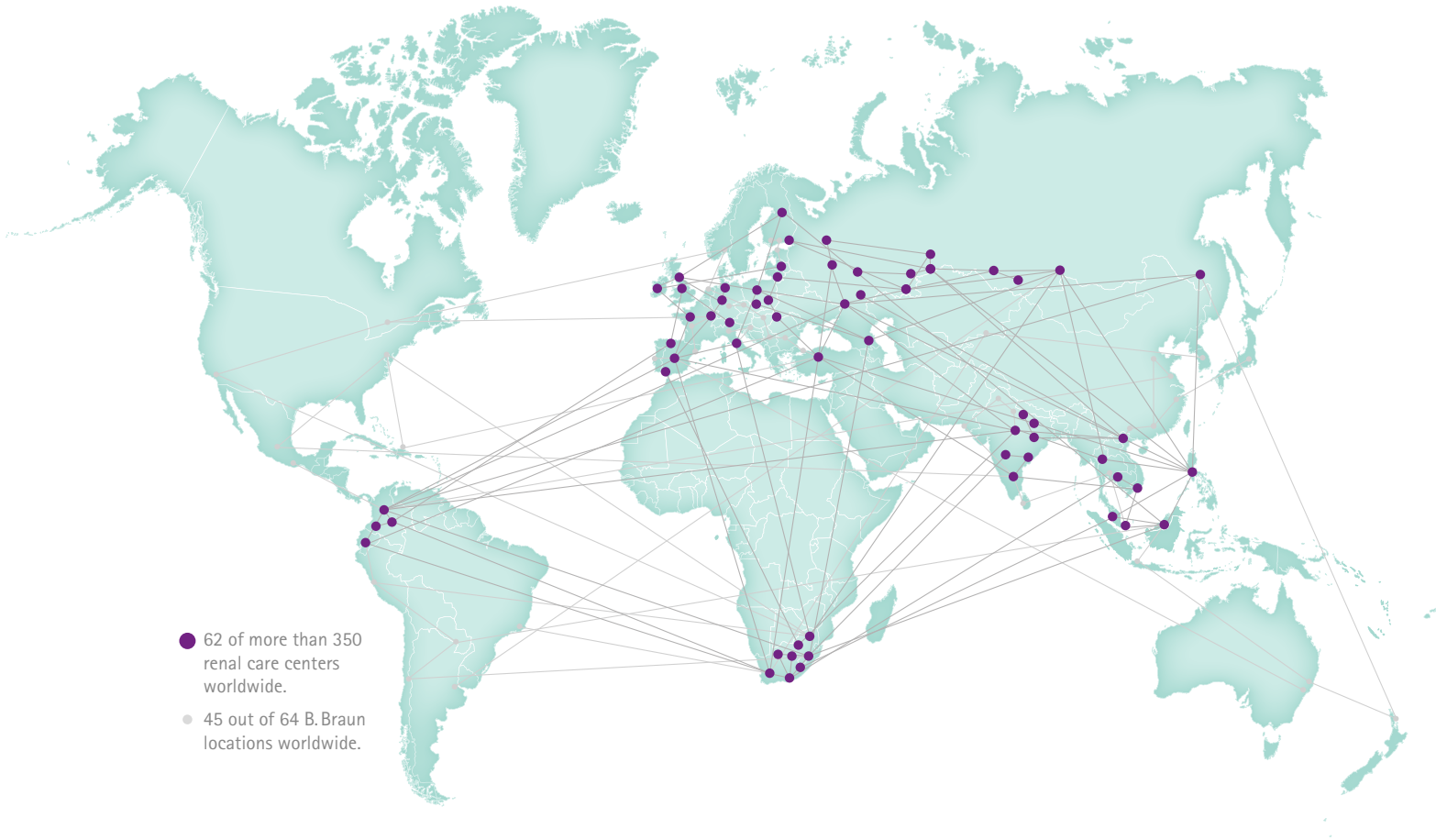
- The right care**
- Moisturizing soap-free cleansing agents
 - Skin oils and body lotions with moisturizing substances
 - Creams containing urea
 - Only take lukewarm showers (no more than 35 °C / 95 °F) and only shower for 3–10 minutes
 - Don't shower daily

- First aid to stop itching**
- Apply a cold washcloth and press it down slightly
 - Create a distraction with moderate physical activity
 - Do some relaxation exercises
 - Don't scratch with your fingers! If absolutely necessary, use a massage glove or a soft brush. Then apply cream to the skin afterward.

Tip: Keep a logbook to record what you eat. It's possible that the itching is triggered by a specific foodstuff.

A NETWORK OF COMPETENCE

Exploring the world with B. Braun



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