#### UCSF Medical Center 加州大學舊金山分校醫療中心

## Your Health Matters: Living with an Ileostomy

您的健康至要: 做迴腸造口術後的生活

**UCSF Medical Center** 

**Your Health Matters** 

Living with an Ileostomy

Most people who have ileostomies continue to have normal lives. They go to work, play sports, have babies and do the things that most people do. That is not to say that having an ileostomy isn't a life-changing experience. It is a life-changing experience, but the changes can be incorporated into your life-style. This booklet is aimed at answering the most common questions and concerns about ileostomy. Please feel free to discuss any of these issues, or issues that aren't addressed here, with your nurse or doctor.

## What you need to know before you leave the hospital

Hospital nursing station:

Who can help with questions or problems:
 Ostomy Nurse Susan Barbour, RN (415)
 353-1085 or Nurse Practitioner Lois Anne Indorf, (415) 885-3613, or

## 加州大學舊金山分校醫療中心 關於你的保健問題的回答和指導 做迴腸造口術後的生活

## 離院前須知

醫護站:

有問題或困難時,提供幫助者是:造口術護士 Susan Barbour, RN (415)353-1085 或 執業護士 Lois Anne In-

- Name of your operation:
- Ostomy supplies you are now using:
- You can buy your supplies at (or they have been ordered from the following supply house)

#### **General information**

An ileostomy is the creation of a passage that brings the end of your small intestine through an opening in your abdomen. The end of the intestine is sewn into place on your lower abdomen - usually your right side- with surgical stitches called sutures. You will have no control over the gas and stool coming out of the opening, which is called a stoma or ostomy. A bag or pouch worn over this opening (attached by adhesive) collects all the gas and stool. Usually people who have an ileostomy have had their colons (large intestines) removed because of Ulcerative Colitis or Crohn's disease. Sometime, an ileostomy is a temporary measure to keep the stool away from a leak lower down in the intestine or to protect an area while it heals. The stool in the small intestine is loose, varying from watery to the consistency of "refried beans." Digestion and absorption of food and drugs takes place in your small bowel with the help of "active" enzymes. The large bowel or colon absorbs water and electrolytes (salt, potassium), stores the stool and inactivates the digestive enzymes. When the large bowel is removed, the stool coming through the ileosdorf, (415) 885-3613, 或

- •你的手術名稱:
- 你現需用的人工造口用品:
- ◆你在何處可購買這些需用品 (或找從下面的日用品商店訂購)

## 一般資訊

迴腸造口術是創建一條通道,將小腸的 末端經過開口引到腹部外 。腸的末端縫 在下腹部,通常是在你的右邊。由於採 用外科縫合法,叫做縫合術。你無法控 制氣體與糞便從 開口端(叫造口)排出。 在開口處佩戴一個塑料袋或小袋用黏合 劑黏貼著,以收集所有氣體與糞便。通 常,做迴腸造口的人們由於有潰瘍性結 腸炎或克羅恩氏(Crohn's)病,也會將結 腸(大腸)切除。有時,迴腸造口是臨時 性的,以避免排糞便滲漏到腸的較下端 或用來保護康復處。在小腸中的糞便是 鬆散的,由水樣到炸菜豆泥般黏稠度之 差異。在活性酶協助下,食物的消化吸 收與藥物處理的地方是在小腸中進行。 而大腸或結腸吸收水與電解質(鹽、 鉀),儲存糞便與使消化酶失活。當大腸 切除後,糞便通過迴腸造口時含有較多

tomy contains more water, salt, potassium and the "active" enzymes. We will show you how to keep this loose stool off your skin so your skin stays healthy. If you still have your rectum, you can expect to have some mucus or blood through the anus. Some people will give themselves a Fleet enema once a week to clean out the rectum.

水、鹽、鉀與活性酶。我們會給你展示如何避免這鬆散的糞便沾在你的皮膚 上,使你的皮膚保持健康。如果你的直 腸仍在,你可以預計會有少量粘液或血 液通過肛門。有些人會每週給自己一次 快速灌腸劑去清理直腸。

Find a Doctor: (800) 444-2559
Patient Education Library:

www.ucsfhealth.org/education

找一名醫生: (800) 444-2559

病人教育圖書館:

www.ucsfhealth.org/education

#### **Common Questions and Answers**

#### How often do I change the pouch?

Change the pouch regularly to avoid leaks. Most people change the pouch every three to seven days depending on their stoma, location and preferences. You will begin to notice when your ileostomy is "quiet," or less active and you can schedule your pouch changes at that time.

#### How do I change the pouch?

The nursing staff will begin to teach you or your family how to change the pouch before you go home. Usually we can arrange for home health nurses to come to your house for continued teaching. Step by step directions on how to change the pouch are at the end of this booklet.

## 常見的問題與解答

## 袋子要多久更换一次?

爲防止滲漏,要定期更換袋子。視乎人們造口、位置與喜好而定,很多人會每隔三至七天更換袋子。你會開始留意到當迴腸造口靜止時或沒那麼活躍時,便正是更換袋子的時候了。

## 如何更換膠袋?

在你出院之前,護理人員會開始指導你或你的家人如何去更換膠袋。通常,我們可以安排家庭保健護士家訪,以提供持續指導。在本小冊子的結尾,附有更換操作步驟的說明。

## 袋子要多久清理一次?

#### How often do I need to empty the pouch?

Empty the pouch when it is one third to one half full. Most people will empty their pouch about five to seven times a day. You may want to place toilet paper in the toilet bowl to prevent splashing when emptying. If the pouch gets very full, there is more chance for leakage, and it is more visible under your clothes.

#### Where do I buy the pouches?

You can buy the pouches at medical supply stores in your area or you can order them through the mail. See the end of this booklet for resources and numbers.

#### Does insurance pay for the supplies?

- Many insurance companies will pay 50 percent to 100 percent of the cost of pouches.
- If you belong to an HMO, they will tell you exactly where to get supplies they will cover.
- If you have MediCal your discharge coordinator will help determine the contracted supplier.
- MediCare pays 80 percent of the cost of

當膠袋達到三分之一或半滿,你就要清理它。大多數人會在一天內清理五至七次。你可考慮在馬桶裡面的水放些衛生紙,以免在清理時濺污。如果袋子過滿,出現滲漏的機會更高,而且,在你的衣物下更顯而易見。

## 哪裡可買到膠袋?

你可以在就近的醫療物料商店買到膠袋,另外,你也可以郵購。請閱小冊子 結尾附有的資料與電話號碼。

## 保險賠償會包含需用品的費用嗎?

- 許多保險公司會支付一半至全部的膠袋費用。
- •如果你是屬於一家 保健組織(HMO)的 話,他們會準確地告訴你那些用旨是 可支付的。
- •如果你有 MediCal(加州的醫療保健計劃白卡),你的出院協調員會幫助你查明有合同關係的供應商。
- ●MediCare(老年保健醫療計劃紅藍卡)會 支付大部份膠袋達八成的費用。每月

most pouches. The monthly allowance includes 20 drainable pouches or 60 closed pouches, 20 skin barriers and one belt. If you have a secondary insurance plan to your MediCare, it will pick up the difference between the actual cost and what MediCare covers.

 An annual prescription for ostomy supplies is necessary. After the first year with a permanent ostomy your primary care provider will write the prescriptions you need for supplies.

## If I don't have insurance, how much do supplies cost?

A typical colostomy pouch costs about \$6. Extra supplies, like paste, powder, adhesive removers, wipes or a belt, add to the cost. It is hard to estimate a yearly cost as different people use different supplies and change pouches on different schedules. A minimum of \$700 to \$1000 per year would be a start.

#### What about odors?

Many years ago the pouches were not odorproof, and people associated ostomies with 的津貼包括二十個可排水的膠袋或六 十個密封膠袋、二十個皮膚屏障與一 條帶。如果你在 MediCare 以外有第二 個保險計劃,他們會負責實際費用減 去 MediCare 的賠償額後之差額。

每年都需要爲造口術所需品開處方。在第一年固定造口術之後,你的主診醫生會給你開所需品的處方。

# 如果我沒有保險,需用品的費用會是多少?

一個普通的結腸造口術膠袋的費用是六元。額外費用的所需品包括膠貼、粉末、除黏合劑、抹巾或帶等。因爲各人可以選用不同的所需品,而且更換袋子的時間次數也有異,所以很難估計周年費用。大約每年起碼最少由 700 元至1000 元。

## 氣味又怎辦呢?

許多年前,這些膠袋並不防臭,而造口 術的人也就伴隨著臭味。今天,新款的 膠袋都是防臭的。除非有糞便在袋子 odor. Today's modern pouches are odor proof and you shouldn't smell anything unless there is stool on the outside of the pouch or on the clip or if the pouch is leaking. It is not unusual to be hypersensitive to odors after surgery. There are deodorants to put in the pouch or tablets you can take by mouth for the odor. If the odor bothers you when you are emptying your pouch in the bathroom, try using pouch deodorants.

## What can I do about the gas and the noise it makes?

Everyone worries about this. The amount of gas you have after the operation is usually more than you will have in a few weeks. The sound of the gas passing will lessen with time. Sometimes putting your arm/hand/handbag/ book right over the stoma when it starts making noise will muffle the sound. If the gas continues and is a problem, avoid foods that cause gas or eat these foods when you don't care about the noise. For example, don't eat beans, broccoli or similar foods that often cause gas before you go out. Avoid carbonated drinks and drinking with straws.

#### Will everyone know I have an ileostomy?

Not unless you tell them. At first, everyone feels that people can see the pouch under

外、夾子上,又或袋子正在滲漏,否則你不應該嗅到任何氣味。手術後,對氣味過敏並非常有。可在膠袋內放置防臭劑,或者你可以口服藥片以防氣味。當你在浴室裏清理膠袋時,如果氣味困擾著你,可試用袋子防臭劑吧。

## 有關腸氣與腸道噪音,我能做些甚麼?

每個人都會擔心這個問題。手術後的幾個星期內,腸氣通常會比較多。氣體通過的聲音會經過一段時間便會減弱。當有腸道噪音時,將手臂/手/養/書放在時是可以掩蓋噪音。如果腸氣持續不斷令人困惑,可避免進食者,或在你不介意噪音時是生氣體的食物。如主食這類食物。例如:外出前,不要吃豆類、椰菜或類似產生氣體的食物。也可避免飲汽水和用飲管喝。

## 其他人會知道我身上有一個結腸造口術嗎?

不會,除非你告訴他們。起初,每個人都覺得人們能看到他們衣服下面的袋子,但過了一段時間,你會明白他們是

their clothes but after a while, you realize that they can't. It will make noises that you will not be able to control. It makes the most noise in the first few weeks after surgery. Eventually, the noises usually diminish and they sound about the same as normal stomach rumbling.

#### What about sex?

Many people feel uncomfortable at first about being intimate when there are changes in their body. You may feel unattractive and that your partner may not want to get close to you anymore. Your partner may be afraid of hurting you, or afraid of your stoma. These are all common feelings. Talk to your partner about your feelings and encourage him or her to share their feelings. Keep your sense of humor and if you need more help, you can talk to an ostomy nurse for resources. Some operations may affect a man's ability to have an erection and may cause pain with intercourse for a woman. Discuss this with your surgeon.

## Can I shower, take a bath or get in a hot tub?

Yes. You can take a bath or shower with or without the pouch. The water does not hurt the stoma and will not go inside. Stool will continue to come out of the stoma so if you want to shower with the pouch off choose a

不會知道的。造口會發出無法控制的噪音;而手術後最初的數個星期 是最多的。最後,噪音通常減少。與胃在平時發出來的聲音大致相同。

## 性事又如何呢?

## 我可以淋浴、浸浴或浸在熱水浴池中 嗎?

可以的。不論帶著膠袋與否,你都可以 浸浴或淋浴。水並不會損傷,也不會進 入造口。糞便仍然會在造口處出來,因 此,如果你不想帶著膠袋淋浴,要選擇 一個造口不排泄時。你也可以帶著膠袋 time when the stoma is inactive. You may enjoy a hot tub/bathtub with a pouch on. If you shower with the pouch, be sure to cover gas filters to avoid getting them wet.

#### Are there certain activities I can't do?

If you have had your rectum removed that area will be tender for a while and you may not be able to ride a bike or a horse until the pain is gone. All other activities are fine including swimming. Check with your surgeon if you have further questions.

#### Do I have to follow a special diet?

- For the first four to six weeks you must avoid a high fiber diet to prevent a blockage right behind the stoma. The abdominal muscle around the stoma is swollen after surgery making the opening narrower than it will be later. This shouldn't be a problem once the swelling goes down. Occasionally a narrow area develops in the small intestine; in that case continued avoidance of these foods may be necessary. In general you can slowly resume eating a balanced diet, but you may wish to avoid certain foods that increase odor or gas, or disagree with you.
- Always watch your fluid intake and drink enough fluids so your urine is light yellow to clear in color to prevent possible formation of kidney stones. If you are exercising or live in a warm climate, you will need more fluids.

享受一個熱水浸浴。如果帶著袋子淋浴,要確保氣體濾器蓋好,以免將其弄濕。

## 有那些活動我不能夠參加?

如果你已切除直腸,一段時間內那部位 仍感疼痛,因此,直至疼痛消退前不可 以騎自行車或騎馬。其他活動都可,包 括游泳。若有其他疑問,可找你的外科 醫生查看。

## 我需要採用一種特別的飲食嗎?

- •在最初四至六個星期內,你必須要避 免高纖維飲食,以免出現造口堵塞。 手術後,造口周圍腹壁 肌肉會腫脹, 總會使開口變窄。當腫脹消退時, 題也隨之解除了。有時,部份小腸 變窄;在這情況下,便有需要繼續 免進食 這些食物。一般情況下,你可 以慢慢恢復均衡飲食;不過,你可能 想避免進食某些會增加氣味 或氣體的 食物,或不適宜的食物。
- 經常留意飲水量,飲足夠的液體,保持你的尿液淡黃至清澈的顏色,以避免形成腎結石。若你在溫暖的天氣下做運動或生活,你會需要飲更多液

 If you are lactose intolerant or are unsure, begin eating milk products slowly. Try changing to fermented milk forms (yogurt, cheese, buttermilk) if you experience bloating, cramping or gas after drinking milk. Soy products or goat's milk may be substitutes.

#### 體。

如果你有或懷疑有乳糖不能耐受,進 食奶類產品要慢慢地開始。若你飲奶 後出現腹脹、腹部絞痛或排氣,可嘗 試改用發酵奶類飲品(酸奶、奶酪、酪 乳)。大豆產品或羊奶也可代替之。

# For the first four to six weeks (and as individually necessary) avoid the following foods:

- Dried fruit
- Green beans
- Tough or large pieces of meat meats with casings
- Chinese vegetables
- Pickles
- Coconut
- Popcorn, nuts and seeds
- Raw vegetables including salad, celery, cole slaw
- Some raw fruit, such as oranges, grapefruit, apples and strawberries
- Cooked corn
- Mushrooms

## 在首四至六個星期内(或就個人需要), 避免進食下列 食物:

- ●乾果
- ●綠豆
- 堅韌或大塊的肉、帶腸衣的肉
- 中國蔬菜
- ●醃漬食品
- •椰子
- 爆玉米花、堅果與籽類
- 未經煮熟的蔬菜,包括涼拌菜、芹菜、酸卷心菜絲
- 一些生的水果、例如:橙、葡萄、 柚、蘋果與草莓
- 煮熟的玉米
- ●磨菇

## Foods which may increase odor

- Asparagus
- Eggs
- Broccoli
- Brussels sprouts
- Fish
- Onion

## 會增加氣味的食物

- ●露笥
- ●雞蛋
- ●椰菜
- 抱子甘藍
- ●魚

Cabbage	<ul><li>洋蔥</li></ul>
• Some spices	●捲心菜(也叫甘藍、洋白菜)
• Cauliflower	●一些香料
• Beans	
	●花椰菜(俗稱花菜)
	<ul><li>● 豆類</li></ul>
Foods that may increase gas	會增加排氣的食物
Apple juice	→ □ □ □
Cauliflower	●蘋果汁
• Beans	●花椰菜
• Corn	●豆類
• Beer	●玉米
• Cucumbers	●啤酒
• Peas	●青瓜(也叫黄瓜)
<ul> <li>Mushrooms</li> </ul>	●豌豆
• Broccoli	●磨菇
Carbonated soda	
Brussels sprouts     Dedictors	●椰菜
• Radishes	●汽水
Cabbage     Dairy products	● 抱子甘藍
Dairy products	●蘿蔔卜
	●捲心菜(也叫甘藍、洋白菜)
	●乳製品
Foods that usually thicken stool	通常會使糞便變稠的食物
Apple sauce	せた 田 4条
• Rice	●蘋果醬
• Bananas	● 米飯
• Bread	●香蕉
• Cheese	●麵包
• Tapioca	●奶酪
Boiled milk	●木薯
• Toast	●煮沸過的牛奶
• Yogurt	●烤麵包片
Marshmallows	●污變也月

- Pasta
- Bagels
- Pretzels
- Creamy Peanut butter

- ●酸奶
- 果漿軟糖
- ●麵條
- 硬麵包圈
- ●椒鹽脆餅圏
- •柔滑花生醬

#### Foods that may loosen stool

- Green beans
- Prunes/juice
- Beer
- Spicy foods
- Broccoli
- Chocolate
- Fresh fruits
- Spinach leafy green
- Grape juice
- Raw vegetables •
- Aspartame / Nutrasweet

## 會使糞便變得鬆散的食物

- ●綠豆
- ●西梅/西梅汁
- ●啤酒
- •辛辣食物
- ●椰菜
- •巧克力
- •新鮮水果
- 菠菜綠葉
- •提子汁
- 未經煮過的蔬菜
- ●阿斯巴甜/天冬甜素(即人造甜味劑、 代糖)

## How do I find out about different types of pouches?

- Nurses who specialize in the care of people with ostomies can tell you about different pouches. These nurses may be referred to as stoma nurses, ostomy nurses, "ET" nurses (short for Enterostomal Therapist) or WOC nurses (Wound, Ostomy and Continence nurses).
- Your nurse practitioner or home care nurse

## 我怎樣才找到不同類型的袋子?

- •專門護理造口術病人的護士能告訴你關於袋子的類型。這些護士也可以被稱爲造口護士、造口術護士、ET護士(腸造口治療師)或 WOC (傷口、造口和失禁) 護士。
- 你的執業醫護師或家庭護理護士也可

can help.

- The United Ostomy Association of American is a good resource for information. www.uoaa.org
- Pouches are either "one-piece" or "two-piece" systems. In a one-piece pouch, the pouch and adhesive are in one piece. A two-piece pouch has a separate adhesive part. There are drainable pouches and closed pouches, short pouches and long pouches, transparent and opaque pouches, pouches with adhesive and those held on by a belt. Your nurses usually will choose the one that best suits your needs before you leave the hospital. You may need or want a different type of pouch later. You may contact the manufacturers of pouches for free samples.
- Some ostomy manufacturers and their tollfree telephone numbers are:

Convatec (800) 422-8811 www.convatec.com
Hollister (888) 740-8999 www.hollister.com
Coloplast (800) 533-0464 www.coloplast.com
Nu-Hope (800) 899-7711 www.nu-hope.com
Cymed (800) 582-0707
www.cymedostomy.com

These companies often provide an advice nurse to help you select a product appropriate for your needs.

以給你協助。

- ●美國聯合造口協會 (www.uoaa.org) 也是一處好的資訊來源。
- •膠袋有"一件"與"兩件"之分。 "一件"袋子的話,袋子與膠貼是一 體的;至於"兩件"袋子,膠貼則是 分開的。袋子也有分爲可排出的和密 對的、短的和長的,透明的和不透明 的、帶膠貼的和用帶去固定的。在你 離開醫院之前,你的護士通常會選擇 一種最適合你需要的。之後,你可能 需要或希望用另一種膠袋,你可與膠 袋製造商聯繫取免費試用品。
- 一些造口用品製造商與他們的免費電話號碼是:

Convatec (800) 422-8811

www.convatec.com

Hollister (888) 740–8999

www.hollister.com

Coloplast (800) 533-0464

www.coloplast.com

Nu-Hope (800) 899-7711 www.nu-

hope.com

Cymed (800) 582-0707

www.cymedostomy.com

#### What if my pouch leaks when I am out?

If you change the pouch on a regular schedule, it shouldn't leak. However, it is always best to be prepared. Keep an extra pouch with you at all times. If your pouch leaks more than very rarely, you should see a specialist nurse for help.

## What can I do if I feel I need more help in dealing with this?

Talking to other people who have had the same operation either in support groups or one-on-one can be very helpful (see the section on Helpful Contacts). Talk with your nurse, the specialist nurse and your friends and family. A referral to a therapist also can be helpful in sorting out all the feelings you may have after your operation. It is perfectly normal to have these feelings and need help in dealing with them.

## What kind of problems can I have in the future?

 Skin Irritation: Skin irritation around your stoma may be due to an allergy to the adhesive, or from using soaps around the 這些公司經常會安排一名指導護士去協助你選擇一些 適合你需要的產品。

## 當我外出時遇到袋子滲漏,怎辦?

若你定期更換袋子,它是不會滲漏的。 不過,最好還是常有準備;任何時候都 要額外備帶一個袋子。雖然甚少滲漏, 如發生時,你應尋求專科護士的協助。

# 如果在處理這問題時我需要更多協助,要怎樣做?

跟其他有相同經驗的人們討論,無論是 在互助小組或是一對一的互助都是非常 有益的(參閱 "有益的聯繫"一節)。 也可跟你的護士、專科護士、你的朋友 與家人討論。轉診給一名治療師,亦會 對處理你在手術後可能產生的各種感受 有幫助的。有這些感受是完全正常的, 因此需要協助去將之化解。

## 我未來會遇上什麼種類的問題?

皮膚刺激:在造口周圍示現皮膚刺激,可能是對膠貼過敏或造口使用肥皂有關,所以,只能用清水洗滌。有時,若袋口太寬,皮膚接觸到糞便,

stoma, so cleanse with water only. Sometimes if the opening of the pouch is too large, the skin can be irritated by its exposure to stool. Measure the stoma and add 1/8 inch to the opening and you will usually not have skin irritation. Contact a specialist nurse if it persists.

- Make sure the pouch opening fits your stoma without actually touching the stoma with no skin showing.
- Expose the irritated skin to air for 20 to 30 minutes during changes.
- Do not use any solvents, sealants or medications on irritated skin unless your doctor or nurse has approved them.
- Call the stoma nurse if redness doesn't go away.
- Hernias: Some people can get a hernia around their stoma. A hernia occurs when the opening in the muscle around the stoma stretches so much that the intestines slip into this hole and cause a bulge. We don't know how to prevent this from happening but it seems sensible to avoid increasing the pressure behind the stoma for 4-6 weeks. For 6 weeks following surgery avoid heavy lifting (more than 10 pounds), excessive coughing, vomiting or straining. Keep your weight in a healthy range.

也會造成皮膚刺激。量度造口,並將 袋口寬度增加 1/8 吋,這樣通常可避 免皮膚刺激。若是刺激持續不斷,可 與專業護士聯繫。

- ○確定袋口寬度與造口是合稱的,也不 會觸及造口,而且不會露出皮膚。
- 當更換袋子時,將受刺激的皮膚在空 氣中暴露 20 至 30 分鐘。
- 除非已得到醫生或護士准許,不要在 受刺激的皮膚上用任何溶劑,封閉劑 或藥物。
- ○若紅腫未能消退,致電造口護士求 助。
- •疝氣:有些人會在造口周圍產生疝 氣。當造口周圍的肌肉過度延伸,因 而腸子滑進這個窩,造成膨出。我們 並不知道怎樣去預防這情況,不過 一個合理的處理方法是在四至六個星 期內避免增加造口後面的壓力。手術 之後的六個星期,要避免提起重物(超 過10磅的)和過量咳嗽、嘔吐或過 勞。將你的體重保持在一個健康的範 圍內。

#### **Helpful Tips and Information**

- Always change a leaky pouch (stool on the skin causes irritation).
- When traveling, carry your supplies with you in case your luggage is lost.
- Always carry an extra pouch in your purse or pocket.
- A small amount of bleeding from the stoma when you clean the area is normal. Do not be alarmed.
- The stoma will change size and shape with weight loss or gain and with pregnancy. You will need to change the pattern or size of the opening to prevent skin irritation if this occurs.
- Your stoma will shrink in size for a while after surgery, mostly in the first month. If you notice skin irritation around the stoma later or notice that the pouch opening seems big, your skin barrier may need resizing.
- Carefully clip or shave the hairs under the pouch area if they interfere with the pouch sticking or if it is uncomfortable to take the pouch off because it pulls the hair.
- It is important that you change the pouch on a regular schedule, approximately every our days. Changing your pouch regularly

## 有益的指導和信息

- 常常更換渗漏的膠袋(在皮膚上的糞便 有刺激性)。
- 外出時,有可能會遺失行李箱,所以,需用品要隨身帶。
- 常常要放置額外的膠袋在錢包或手袋内。
- 清洗造口時有小量出血是正常的,不必擔心。
- 造口的大小與形狀會隨體重與懷孕而 改變;你需要相應改變膠袋口的樣式 與大小以防止皮膚受到刺激。
- 手術後,大多在頭個月內,你的造口 會在一段時間內縮小。若你之後發現 在造口周圍有皮膚刺激情況,或者袋 口大了,你的皮膚屛障大小可能需要 調整。
- 若膠袋下的汗毛髮阻礙袋子黏貼或脱 下袋子時牽拉汗毛感到不舒服,就小 心地將其剪去或刮去。
- 定期更換膠袋是重要的,大約每四天 一次。定期更換袋子應當可以避免意 外的滲漏或刺激皮膚。

should avoid unexpected leaks or skin irritation.

- If the plastic of the pouch causes discomfort or skin irritation, try using a pouch cover. You can make your own, using your pouch as a pattern, or you can buy them already made.
- In case of leakage during the night, place a plastic sheet or plastic garbage bag under your mattress pad.
- Your clothes may seem snug at first because of some overall swelling but you should be back wearing the same clothes three to four weeks after surgery.
- Pre-cut pouches are available once your stoma has stopped shrinking.

- 若袋子塑料部份引起不舒服或皮膚刺激,可試用加一個袋套。你可仿袋子的模式自己製作,也可購買現成的。
- 若在晚間出現滲漏,可放置一塊膠布或一個塑膠垃圾袋在床褥墊下。
- 由於有些腫脹,初時你的衣服覺得似 乎緊身,但是,在手術三至四星期後 你可以穿回以前的衣服。
- 當你的造口停止收縮後,你可以用一 些預裁的袋子。

#### **Managing Diarrhea**

- Don't eat fibrous foods (like raw fruits and vegetables). Take small amounts of tea, boiled milk, 7-up or Gatorade.
- Eat bananas, applesauce, boiled rice, tapioca, or peanut butter, which help thicken the output.
- Drink fluids hourly and add salt to food.
- Notify your physician if diarrhea is severe or lasts longer than 24 hours.

## 處理腹瀉

- 不要進食纖維食物(例如:生的水果與蔬菜)。飲少量茶、煮沸的牛奶、七喜 (7Up)或佳得樂(Gatorade)。
- 進食香蕉、蘋果醬、煮熟的米飯、木 薯或花生醬,這些都會幫助使排出物 變稠。
- 每小時都飲飲料,並在食物中加入鹽。
- •若腹瀉嚴重或維持超過24小時,要通

知你的醫生。

#### **Medications:**

- Do not take laxatives, stool softeners or use enemas. You will never need a "bowel prep" as is sometimes needed for X-rays or surgery.
- Long-acting drugs or timed-release capsules are not well absorbed and should be avoided.
- Check the pouch after taking medication to be sure your medication has not passed through whole without being absorbed by your body.
- Medication that can be crushed, chewed or taken in liquid form may be easiest to absorb.

## 藥物

- 不要服用輕瀉藥、糞便軟化劑或用灌腸劑。有時要做X-射線或手術時,你決不必爲"灌腸做準備"。
- 長效藥或緩釋藥膠囊都不能良好地吸收,應當避免。
- 服藥後要檢查袋子,以查明藥物完全 沒有被你的身體吸收,而排示的情 況。
- ●壓碎、嚼碎或以液體狀服用的藥物都可能是最容易吸收的。

## Special section for those of you with a temporary diverting ileostomy:

The temporary ileostomy is created by bringing a loop of bowel out to the skin. Most people do not notice that there are actually two stoma openings on the abdomen. One opening is where the stool comes out and the other goes down to the area of the bowel that needs time to heal. For the first five days after surgery, there may be a plastic rod under the loop of bowel while the ostomy is beginning to heal. This is slipped out painlessly before you go home. Some stool may get into this other hole and cause you to have stool out your anus. Don't be alarmed but do con-

## 爲臨時改道迴腸造口病人的專述部分:

臨時改道迴腸造口術是將小腸袢到皮膚 創建的。很多人並未察覺腹上其實有兩處造口的孔,一處是糞便的排出口時間,一處是為了往下的腸道部位需要時間造不大力,當時不大力,當時不不大力,一些糞便可能會進入另一些糞便可能會進入另一些糞便可能會進入另一些糞便可能會進入另一些糞便可能會進入另一些土地,導致有糞便從肛門出來。這不必擔心,但要通知造口護士。你需要爲臨時

造口更换袋子,大約每三天一次。你可

tact the stoma nurse. You will have to change your pouch about every three days with a temporary ostomy. You may even need a CONVEX pouch. This is a special pouch that is curved on the back. You also may have diarrhea with these temporary stomas. If you are emptying the pouch more than seven times a day or if you are having trouble with the pouch not lasting more than 1-2 days, call the stoma nurse. When you return for the second operation, the ileostomy is "taken down" and the small intestine is reconnected. This is done through the stoma, usually without opening up the healed incision of the first operation. If you had your entire large intestine removed, the same loose stool that had been coming out of your ileostomy is now passed through the anus. If your large intestine is still in place and your rectum was removed, you will pass solid/semi solid stool through your anus. You will be in the hospital for about four to six days depending upon how long it takes you to be able to eat again. Because the second operation takes about one hour, you will be up and walking much sooner and you will need less pain medication than for the first operation. Except for your IV (intravenous), you will have no tubes or drains. You will be allowed to drink fluids when your bowel function has returned, usually in two to five days. When you can tolerate fluids, your doctor will let you eat solid food.

能需要一個凸型的袋子。這是一個特別 袋子,背後是彎曲的。這些臨時孔口也 可有腹瀉。如果你要在一天内清理袋子 超過七次,或者你正在憂慮袋子不可以 維持超過一至兩天,通知造口護士。當 你回來接受第二次手術時,小腸會重新 接通而迴腸造口會被"拆除"。手術通 常不會打開已癒合的第一次手術之切口 而是通過造口完成的。若你大部份大腸 已被切除,原來從迴腸造口出來鬆散的 糞便,現在同樣而經過肛門排出。若你 的大腸仍在,而你的直腸已切除,你的 糞便會是固體狀或半固體狀,也是經肛 門排出。你會留在醫院大約四至六天, 視情況而定,你甚麼時候可以恢復進 食。第二次手術只需大約一個小時,所 以你很快可以起床散步,而且,你需要 止痛藥的份量也會比第一次手術時爲 少。除弔的靜脈點滴,你不再需要其他 管子或排水管。通常在兩至五天内,你 的腸功能恢復,你能耐受吃流質食物。 當你可以吃流質食物後,醫生會讓你進 食固體食物。

How to get ostomy supplies after you go home:

## 回家後如何取到造口術需用品:

•送你出院時,我們給予的需用品足可

- We will send you home with enough supplies for about five pouch changes.
- The Case Manager will order supplies to be delivered to your home after discharge, or will arrange with a home care agency for a visiting nurse to help with ongoing teaching and supplies.
- Most often you will be set up with a medical supply distributer for ongoing supplies.
   The choice of distributor will depend on your insurance. All the distributors carry a wide range of products to meet your needs.
   Once you are discharged by the visiting nurse, you can arrange for supplies to be delivered monthly or every 3 months, depending on your preference and needs.
- Some mail order/distributors:

Byram Medical Supplies (800) 213-0890 www.Byramhealthcare.com

Shield Health Care (800) 765-8775 www.shieldhealthcare.com

Sterling Medical (888) 907-8775

更換大約五次袋子。

- 你的個案管理員會訂購需用品,在你 出院後送到你家中;或會跟家庭護理 機構安排一名家訪護士去爲你持續的 指導與協助提供需用品。
- ●你很多時候會安排一家醫療用品分銷 商繼續供應需用品。選擇那一家分銷 商要根據你的保險契約而定。所有分 銷商都有應用範圍廣泛的產品以滿足 你的需求。當家訪護士停止服務後, 你便可以自行安排需用品直送給你, 每個月或每三個月一次,視你的喜歡 和需要而定。
- •一些需用品郵購/分銷商的聯繫資料:

Byram Medical Supplies (800) 213–0890 www.Byramhealthcare.com

Shield Health Care (800) 765–8775 www.shieldhealthcare.com

Sterling Medical (888) 907–8775 www.sterlingmedical.com www.sterlingmedical.com

American Ostomy Supply (800) 858-5858 http://aos.dirxion.com

Bruce Medical (800) 225-8446 www.brucemedical.com

Edgepark Medical (800) 321-0591 www.edgepark.com

CCS Medical (800) 260-8193 www.ccsmed.com

Liberator Medical (800) 643-3953 www.liberatormedical.com American Ostomy Supply

(800) 858-5858

http://aos.dirxion.com

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CCS Medical (800) 260–8193 www.ccsmed.com

Liberator Medical (800) 643–3953 www.liberatormedical.com

#### **Helpful contacts**

- UCSF has an "ostomy nurse" also called an enterostomal therapist (ET) nurse or a wound, ostomy, continence (WOC) nurse to help you with this type of surgery. Ask your surgeon to put you in contact with her.
- The United Ostomy Association of America

## 幫助與聯繫

•加州大學舊金山分校駐有 "造口術護士",也稱為造口治療師(ET)護士或傷口、造口術、尿失禁(WOC)護士,去協助你處理這類手術。請向你的外科醫生查詢,安排跟她聯絡。

(UOAA) is a volunteer-based health organization dedicated to providing education, information, and support for those having ostomy surgery. The organization is a wonderful resource. If you join you will receive Phoenix Magazine to help keep you up-todate on ostomy information. They have local and online support groups for teens, over 30s, young adults and gay and lesbian ostomates. The website: <a href="https://www.uoaa.org">www.uoaa.org</a>.

- The Crohn's and Colitis Foundation of America (CCFA) is another support and research funding organization for people with Inflammatory Bowel Disease (ulcerative colitis and Crohn's disease). They can be reached at (800) 932-2423 or on the Internet at www.ccfa.org. The CCFA Northern California contact number is (415) 356-2232.
- American Cancer Society. San Francisco Area call (415) 394-7100, or visit online at www.cancer.org
- We recommend "The Ostomy Book: Living Comfortably with Colostomies, Ileostomies and Urostomies" by Barbara Dorr Mullen and Terry McGinn. It is available at your local library or can be ordered on-line or at

- •美國聯合造口術協會(UOAA) 是一以義工為基礎的健康組織,這組織擁有豐富的資源,致力為接受造口手術人士提供教育、資訊與支持。若你參加,你會收到鳳凰雜誌 (Phoenix Magazine),它會提供有關造口術的最新信息。他們給青少年、三十歲以上、年輕成年與同性戀的造口者提供本地與在線的互助小組。網址:www.uoaa.org
- •美國節段性回腸炎和結腸炎基金會 Crohn's and Colitis Foundation of America (CCFA) 是另一家服務炎症性 腸病[潰瘍性結腸炎和克羅恩氏 Crohn 's)病)]患者的支持與研究基金組織。 他們的電話是 (800) 932-2423,網址 是 www.ccfa.org。這組織的北加州聯絡 電話是(415) 356-2232。
- 美國癌症協會。舊金山地區的電話是 (415) 394-7100,也可查閱其網站 www.cancer.org。
- •我們推薦作者 Barbara Dorr Mullen 與
  Terry McGinn 寫的書 造口術專著 "The
  Ostomy Book: 與結腸造口術、回腸造
  口術及尿道造口術舒適地生活 Living

your local bookstore.

- Many of the manufacturers of ostomy products have educational materials on their websites. The websites are included in this booklet.
- Another website that is helpful is www.C3Life.com

Comfortably with Colostomies, Ileostomies and Urostomies"。你可以在本地 的圖書館内找到,也可以在線或在本 地 書店訂購。

- •很多造口術產品製造商在其網站提供 教育材料。在 本小册子内也有列出他 們的網址。
- ●另一有用的網站是 www.C3Life.com。

#### How to change the pouch: One-piece pouch

Collect supplies:

- Pouch
- Plastic bag for disposing of used pouch
- Clamp closure
- Scissors
- Water and tissues Pattern or template
- 1. This is often done at your sink in the bathroom.
- 2. Gently remove the pouch you are now wearing by using both hands, one hand pulling off the pouch while the other is pushing the skin away from the pouch. Be sure to remove the clamp to use on your next pouch.
- 3. Cleanse the skin around your stoma with

## 如何更换袋子:一件裝的

收集物料:

- 袋子
- 用以裝載丢棄舊袋子的膠袋
- 封鉗
- ・剪刀
- · 水與紙巾 · 模板
- 1. 這通常是在浴室的洗滌盆上進行。
- 2. 用雙手輕輕地除去你身上戴著的袋 子,一隻手脱下袋子,而另一隻手則 將皮膚與袋子分開○要記得留下封 鉗,以用在下一個袋子。
- 3. 用暖水清洗造口周圍的皮膚。肥皀會 在皮膚上留下油性殘留物,今到袋子

warm water. Soap can leave an oily residue on the skin and keep the pouch from sticking. Some soap also may cause skin sensitivity from the chemicals in the soap.

- 4. Pat the skin dry using tissues, a towel or a hair dryer. The skin must be absolutely dry or the adhesive will not stick to the skin.
- 5. If you already have a pattern, check to make sure it is still the right size by placing it over the stoma and seeing if there is any skin exposed. Transfer the correctly sized pattern to the back of the pouch and trace the pattern onto the paper backing of the adhesive. Cut a hole in the skin barrier that matches the pattern. Check the cut opening to your stoma before taking the paper off to ensure a good fit.
- 6. Remove the paper covering on the back. If you use Stomahesive paste, squeeze it around the cut opening about 1/8 to 1/4 inch thick. If the paste is hard to squeeze out, put it in a glass of hot water for a few minutes to soften it. Once the pouch opening fits well, clean the skin again if there is some mucus or stool on the skin.
- 7. Center the pouch opening over the stoma and press it against the skin. Press the tape against skin, working from stoma to the outside of the wafer.

- 難以黏貼。有些肥皀內的化學物也可能會導致皮膚過敏。
- 4. 用紙巾、毛巾將皮膚輕拍至乾或用乾 髮器吹乾。皮膚一定要完全乾透, 否則黏貼不能黏上皮膚。
- 5. 若你已經有一個模板,要放在造口上,檢查一下以確定它的大小是否仍然合適,並且看看皮膚有否外露。將符合尺寸的模板放到袋背,然後將模板在黏貼的紙背上描繪。在皮膚屛障内切一個相配模板的孔。將紙撕去之前,檢查切口是不是符合你的造口形狀,要確保是相當合身的。
- 6. 將套背後的紙撕去。若你用施貴實防漏膏 Stomahesive,在切口周圍要擠壓成大約 1/8 至 1/4 吋厚。如果擠膏遇到困難,可將它放在一杯熱水內數分鐘,令其軟化。當袋口形狀符合造口時,如果皮膚上有粘液或糞便,可再清潔皮膚一次。
- 7. 將袋口中心放於造口上,然後對著造口邊的皮膚按壓。從造口至護墊的外面,對著皮膚按壓紙邊。

- 8. Attach pouch to the flange on skin barrier. Place lower end of pouch gasket against lower portion of flange. Exerting pressure with your fingers and thumbs, press flange and gasket together. Then, work your way completely around flange, pressing gasket in place until it is securely sealed. Test by pulling outward on the pouch while holding the flange. Attach the clamp or turn the valve to the closed position, depending on type of ostomy.
- The pouch must be emptied when 1/3 to 1/2 full or the weight will weaken the seal and the pouch might leak. To empty the pouch, sit on toilet, remove the clamp and empty contents into toilet.
- 10. Clean the bottom of the pouch with toilet paper. The tail end must be absolutely clean or there may be an odor.
- 11. Change the pouch one or two times a week, or as needed, to prevent leakage.

- 8. 將袋子附在皮膚屏障的邊緣上。放置袋子密封墊的下端對著屏障邊緣的下部。用手指和姆指用力壓,將邊緣與對墊合起來。然後,完全圍繞著邊緣,用你的手按壓封墊,直至牢固地密封爲止。按住邊緣,將袋向外拉進行檢查。根據造口術的類型,裝上袋鉗或轉動活塞至關上的位置。
- 9. 當袋子 1/3 或半滿時,必須要清理, 否則,它的重量會令封條漸漸失效, 袋子可能會滲漏。要清理袋子,坐在 馬桶,除去袋夾,然後將袋子內的全 部倒入馬桶內。
- 10.用紙巾清理袋子底部。其末端必須完 全清理,否則可能會產生氣味。
- 11.一個星期要更換袋子一至兩次,或在必要時更換,以防渗漏。

#### How to Change the Pouch: Two-Piece Pouch

#### Collect supplies:

- Pouch and skin barrier with flange
- Plastic bag for disposing of used pouch
- Clamp closure
- Scissors
- Water and tissues
- Pattern or template

## 如何更换袋子:雨件装的

### 收集物料:

- •袋子與帶邊緣的皮膚屛障
- •用以裝載丟棄舊袋子的膠袋
- ●封袋鉗
- 剪刀
- 水與紙巾

- 1. This is often done at the sink in your bathroom.
- Gently remove the pouch you are now wearing by using both hands, one hand pulling off the pouch while the other is pushing the skin away from the pouch. Be sure to remove the clamp to use on your next pouch.
- Cleanse the skin around your stoma with warm water. Soap can leave an oily residue on the skin and keep the pouch from sticking. Some soap also may cause skin sensitivity from the chemicals in the soap.
- Pat the skin dry using tissues, a towel or a hair dryer. The skin must be absolutely dry or the adhesive will not stick to the skin.
- 5. If you already have a pattern, check to make sure it is still the right size by placing it over the stoma and seeing if there is any skin exposed. Transfer the correctly sized pattern to the back of the skin barrier with flange and trace the pattern onto the paper backing of the adhesive. Cut a hole in the skin barrier that matches the pattern. Do not cut beyond the circular line indicated on the paper backing. Check the cut opening to your stoma before taking the paper off to ensure a good fit.

## ●模板

- 1. 這通常是在浴室的洗滌盆上進行。
- 用雙手輕輕地除去你身上戴著的袋子,一隻手脱下袋子,而另一隻手則將皮膚與袋子分開。要確保除去鉗子,不留下次用。
- 3. 用暖水清洗造口周圍的皮膚。肥皀會在皮膚上留下油性殘留物,使袋子難以黏貼。有些肥皀內的化學物也可能會導致皮膚過敏。
- 4. 用紙巾、毛巾將皮膚輕拍至乾或用乾 髮器吹乾。皮膚一定要完全乾透, 否則黏貼不能黏上皮膚。
- 5. 若你已經有一個模板,放在造口上, 檢查一下以確保它的大小仍然合適, 並且看看皮膚有否外露。將符合尺寸 的模板放到附有邊緣的皮膚屏障背 後,然後在黏貼的紙背後描繪模板。 在皮膚屏障內剪一個相配模板的孔, 但不要剪越過紙背上周線的標示。將 紙撕去之前,檢查切口是不是符合你 的造口形狀,要確保大小應是相當適

- 6. Remove the paper covering on the back. If you use Stomahesive paste, squeeze it around the cut opening about 1/8 to 1/4 inch thick. If the paste is hard to squeeze out, put it in a glass of hot water for a few minutes to soften it. Once the barrier opening fits well, clean the skin again if there is some mucus or stool on the skin.
- 7. Center the skin barrier opening over the stoma and press it against the skin. Press the tape against skin, working from stoma to the outside of the wafer.
- 8. Attach pouch to the flange on skin barrier. Place lower end of pouch gasket against lower portion of flange. Exerting pressure with your fingers and thumbs, press flange and gasket together. Then, work your way completely around flange, pressing gasket in place until it is securely sealed. Test by pulling outward on the pouch while holding the flange. Attach the clamp or turn the valve to the closed position, depending on type of ostomy.
- 9. The pouch must be emptied when 1/3 to 1/2 full or the weight will weaken the seal and the pouch might leak. To empty the pouch, sit on toilet, remove the clamp and empty contents into toilet.

合的。

- 6. 將背後的紙撕去。若你用施貴實防漏膏 Stomahesive,可在切口周圍擠壓成大約 1/8 至 1/4 吋厚。如果擠膏遇到困難,將它放在一杯熱水內數分鐘,令其軟化。當屛障口安置妥後,如果在皮膚上有粘液或糞便,可將皮膚清潔一次。
- 将皮膚屏障中心放於造口上,然後對 著皮膚沿屏障按壓。從造口至護墊的 外面,對著皮膚按壓紙邊。
- 8. 將袋子附在皮膚屏障的邊緣上。放置 袋子密封墊的下端對著屏障邊緣的下 部。用手指和姆指用力壓,將邊緣與 封墊合起來。然後,完全圍繞著邊 緣,用你的手適當按壓密封墊,直至 牢固地密封爲止。按住邊緣,將袋向 外拉進行檢查。根據造口術的類型, 裝上鉗或轉動活塞至關上的位置。
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- 10. Clean the bottom of the pouch with toilet paper. The tail end must be absolutely clean or there may be an odor.
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- 10.用紙巾清理袋子底部。其末端必須要 完全清理,否則可能會產生氣味。
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