

Toileting self-care methods for bilateral high level upper limb amputees

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Abstract

One of the most important problems for the bilateral upper limb deficient patient is the inability to manage toileting activities. Dependence in this area precludes schooling or work. This paper surveys available clothing types and adaptations to facilitate doffing and donning clothing and devices for genital cleansing and menstrual care. The devices are analyzed for suitability for different types and levels of high deficiency and purposes. Independence requires intense motivation of the patient and elimination of overprotection by the parents.

Introduction

The problem which is of greatest concern for the bilateral high level upper limb amputee is the ability to take care of himself in toileting. The inability to cleanse oneself after defecation, urination, and menstruation, eliminates the possibility of attending school, independent travel, or employment. While it is occasionally acceptable to consent to being fed by someone else, it is degrading and destructive of self-confidence for an individual to have to be cared for in the most intimate of activities, toileting. This aspect is frequently ignored by members of the rehabilitation team because toileting activities are considered "dirty". Rehabilitation requires that the rehabilitation team be concerned with successful function in this as in other abilities.

The problem exists mainly in congenital limb deficiency, although an occasional acquired amputee will have a similar problem. The principles are the same, except that in the adult the range of motion of the lower limbs will generally be more restricted.

These persons must be assessed individually. The precise length of the residual limbs, the range of motion of each joint, the muscle strength and agility remaining are crucial. For that reason, only general classifications can be given, and a series of trial methods and devices may be required in an individual case. The purpose of this article is to attempt to disseminate the information that the author has gathered over a prolonged period of time from many sources, so that the therapist working anywhere will have the combined experience of many rehabilitation facilities.

In the rehabilitation of the high bilateral upper limb amputee, the success achieved is directly related to the motivation. The motivation of the child is to a great extent a reflection of the motivation of the parents. If the parents wish the child to attend school, then as a rule the child will be motivated to attend school and to learn those things which are required in order for him to do so. One of these is the ability to take care of himself in the toilet. The patient who is strongly motivated towards independence will usually succeed in being independent despite very severe handicaps. If the parents want to keep the child dependent, they will generally succeed in so doing, often for life. This precludes independence in the activities of daily living, in schooling and in vocational training and placement.

Preparation for toileting activities

Before toileting can be started, the clothing and underclothing must be removed. For the young child clothing adaptations are almost always required. When the child reaches adolescence and starts to consider social activities, clothing adaptations are frequently rejected because of their unsightly appearance. Clothing adaptations should be as inconspicuous as possible. Required loops should be made from

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the material of the clothing so as to be inconspicuous; Velcro closures should be the same colour. As few special devices as possible should be used, so that they do not have to be carried to school, to work, or while travelling. Loose clothing without elastic is desirable, to make doffing and donning easier.

In the male who needs to urinate, if the zipper cannot be opened by the extremities, either without or with a loop on the zipper pull, the trousers may be left partially open. Provided the upper part of the trousers is covered by an exterior shirt or jacket, the fly of the trousers may be left two-thirds open to allow a boy without arms to urinate independently. The individual will generally not wear underpants. The pants are suspended by means of suspenders rather than a belt. The cross of the suspenders in the back must be quite high to prevent sliding off, usually just below the seventh cervical vertebra. The tension must be just appropriate to suspend the trousers. The trousers are pulled down by having the individual slip off one shoe and grasp the pants leg on the contralateral side with the toes and pull down the trousers, exposing the penis in the already open fly.

In patients with partially functional upper limbs, the fly of the trousers may be entirely closed, to be opened by the upper limbs with or without a limb extender. This is generally facilitated by use of a small key ring in the zipper tab.

For defecation the pants will have to be removed completely. The pants can be closed with Velcro at the waistline, usually with a counter-pull through a D-ring or overlapping. Belt loops and occasionally other loops may be required for donning the pants either with the residual limbs or with a limb extender. Because this is difficult, it is preferable for the individual to be trained to have a bowel movement either in the morning before leaving the house or in the evening after returning, rather than during the school or work day. The pants are generally donned by placing them on the floor or mattress. The patient inserts the feet into the trousers and raises his legs. Gravity and shaking cause the pants to slide proximally while the patient lies supine. When the pants are at the level of the hips, the patient utilizes friction between the mattress or floor and the trousers to hold them in place while wiggling the buttocks into the upper part of the trousers. If suspenders are used to

hold up the trousers, one shoulder is inserted at a time under each suspender strap. This may be assisted by means of the contralateral foot and/or use of the teeth or occasionally the chin. Sometimes the pants are pulled over the hips while standing, pulling up the suspenders with the teeth while rotating the hips with the legs in maximal abduction.

Occasionally a boy wishes to wear his shirt inside his pants. This increases the difficulty in dressing. Long elastic straps should be sewn to the shirt at the hemline. These loops are held with the toes while the trousers are donned.



Fig. 1. Devices from the Rehabilitation Institute of Montreal. Left, clothing hook attached to mirror. Right, device for patients with short upper limbs (see text).

Devices

Devices may be utilized to facilitate doffing and donning of clothing. The simplest one that will do the job is best. The most useful is a clothing hook on the wall at the appropriate level for the individual. The hook may be of any shape. It may be plain, roughened or have rubber tubing. Monique Audet at the Rehabilitation Institute of Montreal, Canada, applies the hook to a mirror with a suction cup so that the individual can see where the hook is in relation to the clothing. (Fig. 1 left). They also developed a device for patients with short upper limbs, especially phocomelia. It is a forked rod to push the trousers down. (Fig. 1 right). One side of the fork has a hook on it to be used for pulling. The other end of the rod has a cup which the patient applies to his chin forcing the cup and rod down to lower the clothing. In addition, there are

dowels through the rod which are manipulated by the phocomelic extremity and assist in pulling or pushing. A modification was described by Ring (1972) which is a rod connected to an S-shaped curved hook with the S being on its side to push and pull.

M. A. Mendez at Queen Mary's Hospital, Roehampton, London, England, has developed many devices and methods for these patients. Patients with upper limb phocomelia and normal lower limbs use a dressing stick with a hook, S-shaped as described by Ring, but retractable and lockable, or round. Patients with amelia who do not have an upper extremity with prehension use wall hooks and a dressing stick with a biting tip. She adapts the clothing using Velcro usually with counterpull, but occasionally overlap. She occasionally uses Velcro with two loops and a split ring. She illustrates a German wall hook for dressing and undressing which is attached to a wall. This is a flat disc on a rod which is attached to the wall for raising and lowering the clothing (Fig 2).

Ann G. Fisher, Area Child Centre, Grand Rapids, Michigan, has used various shaped plastic limb extenders with a split at the distal end for pushing pants up and down.

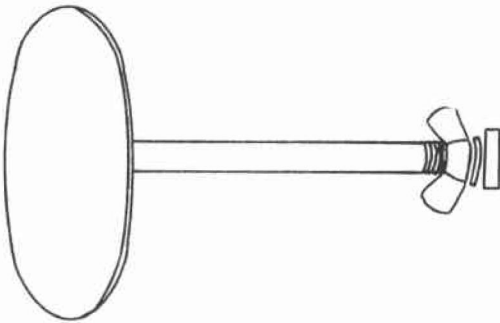


Fig. 2. Wall mounted disc for dressing and undressing used at St. Mary's Hospital, London.

Toileting

There are three categories of patients who have toileting problems. The first is (A) children who have short upper limbs, sometimes with true phocomelia, with adequate grasp and release, but who lack the limb length and reach to cleanse after defecation. The second category (B) is children who have inadequate grasp and release in the upper limbs, who have limited range of

motion of the hips and/or severe shortening of the femur or of the tibia. The third category (C) is children who have no upper limb function with normal lower limbs and with well developed foot function. Any child who can manage to cleanse the groin area without devices should do so. Foot usage is usually adequate, with trunk motion where needed.

(A) Short arms with grasp

One may have to extend the length of the upper limbs artificially using some type of limb extender for pushing clothing down and pulling it up with an individually designed device for holding the toilet paper.

If the devices cannot be collapsed for carrying, two sets are required, one for home and one for school. Simple ones may be made from $\frac{1}{2}$ " (1 cm) diameter dowel with an L-shaped hook, covered with rubber tubing, or with a coat-hook bent at an appropriate angle depending on the configuration of the patient.

Useful suggestions for wiping devices have been received from many sources. Bridget Duckworth at the G. F. Strong Rehabilitation Centre, in Vancouver, Canada, has found useful a limb extender made of stainless steel welding rod inserted into a plastic or wooden handle. (Fig. 3). A J-cloth (Handi or Easy Wipe) is inserted into the end and wrapped around the prongs. The patient wipes with one part of the cloth, flips the end over and uses a clean part. M. A. Mendez uses a dowel handled extender which has a similar spring metal coil for inserting toilet

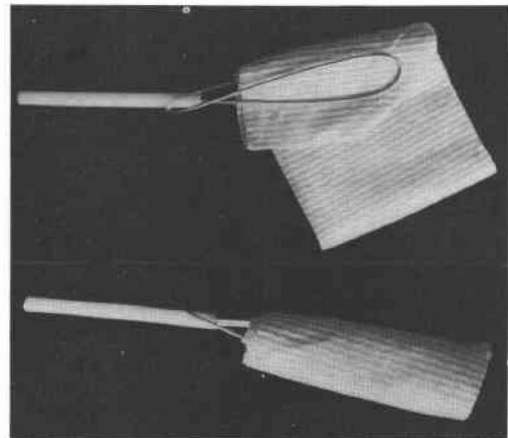


Fig. 3. Stainless steel limb extender from the G. F. Strong Rehabilitation Centre, Vancouver (see text).

paper. Black Notley Hospital, Braintree, England, use a toilet paper holder made out of a stainless steel knitting needle set in an aluminium tubing handle (Lowman & Klinger, 1970). Y. Cupid at the University of Saskatchewan University Hospital in Saskatoon, Canada, recommends a long-handled holder made of coat hanger wire with a coil into which toilet paper is placed, also similar to the preceeding two. A second device which has been used by them is a pair of long-handled tongs bent to the desired shape. This is sometimes difficult to control if the patient uses a prosthetic terminal device.

For travelling, Duckworth has used a washing aid consisting of a long towelling washcloth with one end hooked to the shower head at the top and the lower end attached to two large suction cups which are fixed about half the length of the bathtub. With this, every area can be washed, including the perineal area. It is generally fixed in place by the feet or prostheses. As with most centres, they find wrist flexion units helpful in manipulating trouser zippers if prostheses are used. The zipper tabs are fitted with a small split ring or loop for additional assistance. The wrist flexion units are also helpful for extracting the penis. Some patients are agile enough to use the prosthetic hook for wiping.

All wiping of the anus should be done from the rear in females to avoid vaginitis.

M. Audet uses a portable plastic stick or spatula with a slit or hole at the functional end, into which toilet tissue is inserted. The limb extender is modified according to each child's special needs in length, shape, material, size, etc. As with most centres, they find that collaboration between the therapist, the parents and the child is required for success with these devices, because many types need to be tried before appropriate ones are finally developed. They produce devices that are simple, usable in most situations and easy to transport in a purse or schoolbag so that multiple devices are not required.

Helen J. Scott of Princess Margaret Rose Orthopaedic Hospital in Edinburgh, Scotland, uses a metal folding extender which has a metal ring attached to its end. Stitched to this is a rubber or plastic material which has a central hole with eight or more slits radiating out towards the metal ring. The toilet paper is pressed into the central hole, where it is gripped by the plastic. The child utilizing this device can

reach from the rear for anal cleansing. The toilet paper can be removed by the phocomelic digits and thrown away and a clean piece inserted for further cleansing. The device can be folded for carrying in the schoolbag or purse. Proximal rings or assistive holding devices can be utilized where there is inadequate grasp.

Granstrom (1976) has described two reaching devices. The first is essentially a bent plastic tube with a wooden handle with a narrow slit at the end for holding the toilet tissue. The toilet paper is removed after use by pulling the plastic holder against the rim of the toilet bowl forcing the paper into the bowl. The second device is similar, but the ends of the slit are held close together by means of a sliding plastic ring, securing the toilet tissue during the wiping process. When the toilet tissue is to be disposed, the plastic ring is pushed proximally and the tissue is removed by use of a spike within the removable wooden handle.

Adenia Spencer of the Texas Scottish Rite Hospital for Crippled Children, Dallas, Texas, has tried a jointed rod held together by a wing nut for adjustment of the angle which has a foam covered rectangular plate attached to the end. The foam rubber is covered by a terry cloth cover with a draw string which is used for wiping (Fig. 4).

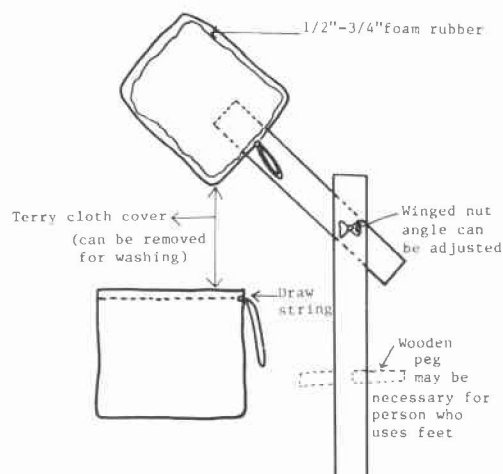


Fig. 4. Adjustable toilet device used at the Texas Scottish Rite Hospital for Crippled Children, Dallas. The size may be adjusted to suit the patient.

Marion Shaw of the Ontario Crippled Children's Centre, Toronto, Canada, has developed a folding rod with a cup and cover similar to the device described from the Princess Margaret Rose Hospital. This device is hinged for portability and is held in the extended position by means of a sliding cylindrical lock. A removable probe for removing the toilet tissue from the cup is inserted into a flat rectangular handle (Fig. 5).

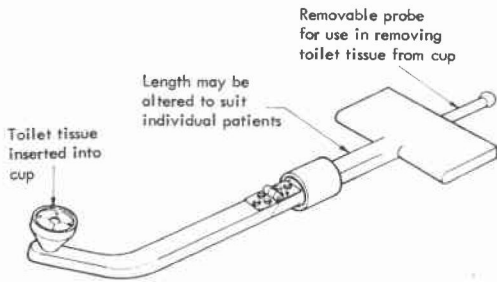


Fig. 5. Ontario Crippled Children's Centre folding rod device.

The Therafin Corporation, Crete, Illinois, has developed a toileting assist they call a Hygiene-Aid, cat. #A131. (Fig. 6, top). It is a rod which has two polyethelene hand straps to assist the patient with limited hand function in grasping the rod. The distal end has a gripping device with plastisol covered jaws which are held together by means of a rubber band. After wiping, the patient taps the release lever on the inside of the toilet bowl to release the paper.

This device is listed in the catalogue of the Fred Sammons Co., Springfield, Illinois. A second toilet limb extender is shown "Short toilet aide" cat.#BK 6014, which is a pair of curved handled tongs covered with plastisol, a positive grip device (Fig. 6, bottom).

Kuhn (1970) of the University of Muenster, illustrates a reaching device which has a pincer to hold the toilet tissue. A button on the proximal end controls the pincer to lock or unlock the toilet paper. It is used from the front.

M. Zimmerman, Institute of Rehabilitation Medicine, New York City, uses a limb extender made of two plastic rods, with smooth edged inter-locking teeth. The handles are squeezed to open, a small spring under the expansile tension closes and holds the paper (Fig. 7, top).

The author made an extension device for an elbow disarticulation stump out of an E-Z band

applicator with elongated handles and rubber tubing covering the curved tips for better prehension (Fig. 7, bottom).

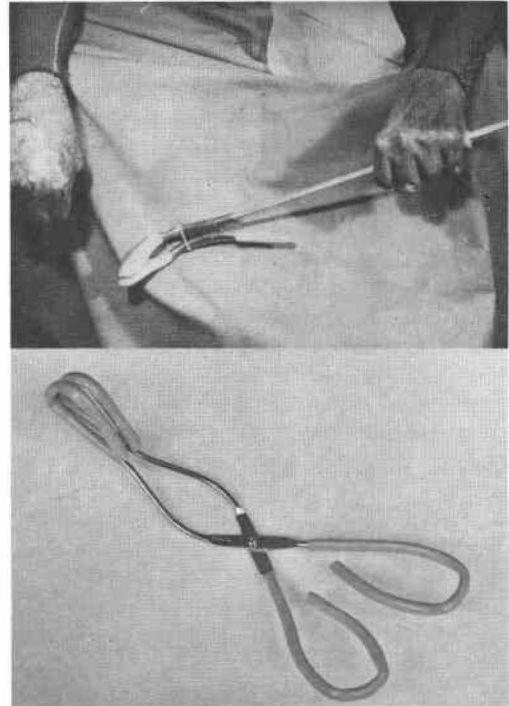


Fig. 6. Top, Therafin Corporation Hygiene-Aid (see text). Bottom, short toilet aid from Fred Sammons Co.

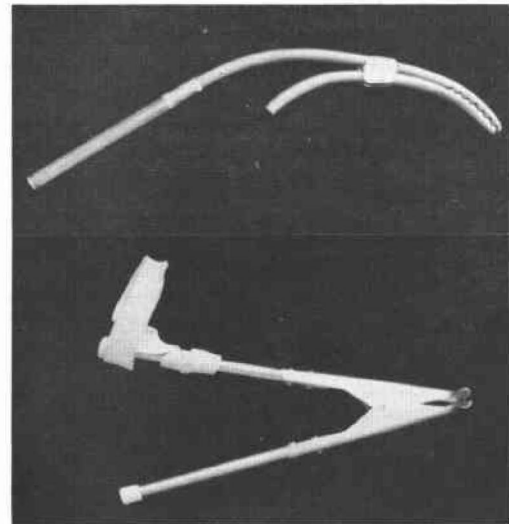


Fig. 7. Top, limb extender used at the Institute of Rehabilitation Medicine, New York. Bottom, the author's device for elbow disarticulation stump.

Elaine Treffer at the University of Tennessee Centre for the Health Sciences in Memphis, Tennessee, uses a modified version of the O.C.C.C. toileting aid. It is made of metal rather than plastic and utilizes a telescoping device rather than a folding one. She finds that this is lighter, smaller and more useful for transporting the device. The proximal side has push and pull hooks for manipulating the pants. She asserts that attempting to train children earlier than the teens in self care is unrewarding because most children younger than the early teens are not adequately motivated for independent toileting. In the author's experience there are some children younger than 13 who are very interested in toileting independence and an attempt to train the child should be made.

(B) Hands with inadequate grasp

The next category of patients are those with upper extremities with inadequate grasp and release with, in addition, limited range of motion at the hips, knees and/or severe shortening of the femur. The best solution is to place the toilet tissue with the hand or the foot on the edge of the toilet bowl and rock the pelvis back and forth against the toilet paper for cleansing the groin. The best type of toilet is of horseshoe shape, preferably with the seat open in front. Some therapists have used the toilet seat rather than the top of the bowl; in the author's experience the top of the bowl is better because it is narrower and it is easier for anal cleaning to take place.

If the above option is not feasible, a stationary device may be required, where ever the child needs to use the toilet.

Prof. E. Marquardt of the University of Heidelberg, Germany, utilizes a plastic device which may be attached to the toilet bowl by means of a spring-clip or to a wall (Fig. 8, top) so that it can swing out for use. A spring plate holds the toilet tissue in a location which the patient can reach with the perineal area. The paper is inserted and removed either by a phocomelic extremity or by use of the feet while the child sits on the toilet nearby (Fig. 8, bottom).

Evelyn Bloch of the Thoms Rehabilitation Hospital, Inc., of Asheville, North Carolina, has described the use of a large diameter dowel fixed to the wall at groin height. The dowel is wrapped with toilet paper using the toes. The toilet paper is sat on to rub the appropriate area. A small

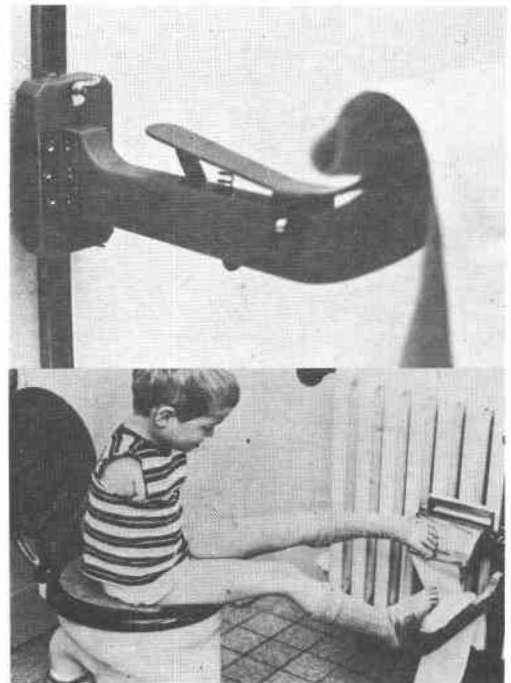


Fig. 8. Wall mounted plastic device from the University of Heidelberg; the device may also be attached to the toilet bowl by spring clips.

enlargement may be added to the dowel near the wall to provide better contact in the anal area.

M. A. Mendez describes two types of split hooks which are attached to a wall either by a suction cup or screws. Essentially they are two flat plates of plastic or metal between which the toilet paper is placed.

The author has described a toilet attachment which hooks on to the edge of a bathtub (Friedmann, 1975). This was modified later by Wright (1976) for use with a floor stand.

Prof. G. G. Kuhn, from the Orthopaedic Hospital of the University of Muenster, Germany, employs a bidet of the WC-O-Matic type. In Scandinavia and in Scotland, the Clos-O-Mat automatic bidet is utilized. (Orthopaedic Hospital, Copenhagen, Denmark, found this unsatisfactory; it can only be used in the home).

(C) No hand function

For patients with little or no upper extremity function on either side with normal lower limbs with well developed foot function, the best

solutions are holding the toilet paper between the toes and wiping the groin with foot and ankle motion while sitting on the floor or the toilet bowl, rocking the pelvis back and forth if needed. Another method requiring less agility is to place the toilet paper over the heel and squat down so that the anal area rests on the paper on the heel. The patient then rocks, cleansing the anal area.

Urinary devices for boys

Boys with phocomelic extremities have the problem of removing the penis from the trousers for urination. Ann G. Fisher suggests the use of a rod with a loop to fish the penis from the trousers after the fly has been opened.

The author's modification involves attaching a Nyloplex cylindrical loop by means of an extension to two or more sections of a folding ruler (Fig. 9). The resulting device is portable and inexpensive.

Ring (1972) shows rods with rings or a gutter trough for holding the penis.

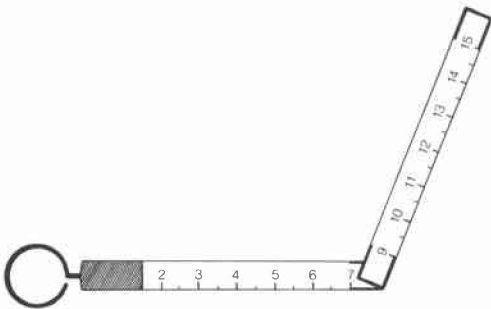


Fig. 9. Simple, inexpensive urinary device modified by the author from the loop and rod aid suggested by the Area Child Centre, Grand Rapids, Michigan.

Menstrual care

A very serious problem for the girl after puberty is cleanliness during the menstrual period. A number of commercial devices may be utilized such as adhesive sanitary napkins inside the panties. A second solution is to use the standard sanitary napkin held inside the panties by means of two elastic strips or pockets (Fig. 10). In an active girl, if there is a problem of shifting, the use of sanitary panties or panties with a plastic crotch may be advisable. Helen J. Scott at the Princess Margaret Rose Orthopaedic Hospital in

Edinburgh, Scotland, suggests that sanitary napkins or towels with loops be held in the panties by means of a cloth strip with a plastic ring on one end. The cloth strip is folded upon itself with two pieces of Velcro to enclose the loop on each side of the napkin. It is held fast to the panty by the stitched on plastic ring. Exact positioning of the sewn straps is important to ensure that the napkin is not displaced during activity.

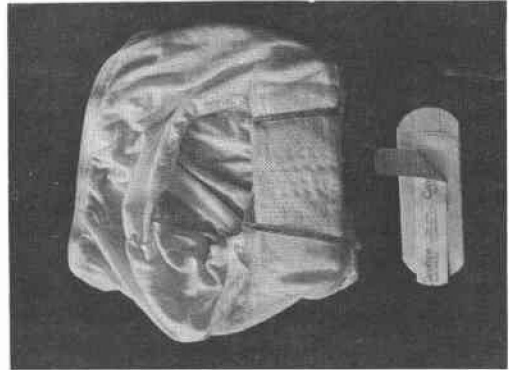


Fig. 10. Sanitary napkin attached to panties by elastic strips.

One useful measure is to use pre-prepared paper panties and adhesive sanitary napkins. The entire panty is thrown away after use.

Some girls prefer the use of a tampon. Where this is desired a mirror should be attached in front of the toilet bowl to assist insertion and removal. Kuhn (1977) illustrated a device he developed for insertion of a tampon into the vagina (Fig. 11, top). It is operated by foot pumping which compresses air which is driven through a tube. The compressed air inserts the tampon rapidly. For this reason there is some potential danger because of the possibility of damage to the skin or to the vaginal tissues. A simpler modification which is portable (Fig. 11, bottom), has been developed by Prof. E. Marquardt which is an additional tube attached to the portable toilet device described earlier for use by phocomelics, with a metal loop for removal. The tampon string is elongated and at its end has a glass bead or metal ring to hook onto the metal loop of the tampon-aid.

Evelyn Bloch sent an idea which she has not tried, which might prove useful. She recommends that for removal of a tampon, which has a double string with a knot dangling, a

small metal hook covered with polyurethane could be attached to a wooden platform which is held down by the feet. The patient could squat over it and catch the hook in the loop and then slowly stand, pulling the tampon out of the vagina. She suggests that perhaps a tube covered with plastisol could be attached to the same board at an angle which is proper for vaginal insertion. This is merely an idea which would need further development.

The Hygiene-Aid made by the Therafin Corporation is claimed to be successful for inserting and removing vaginal tampons (see Fig. 6, top).

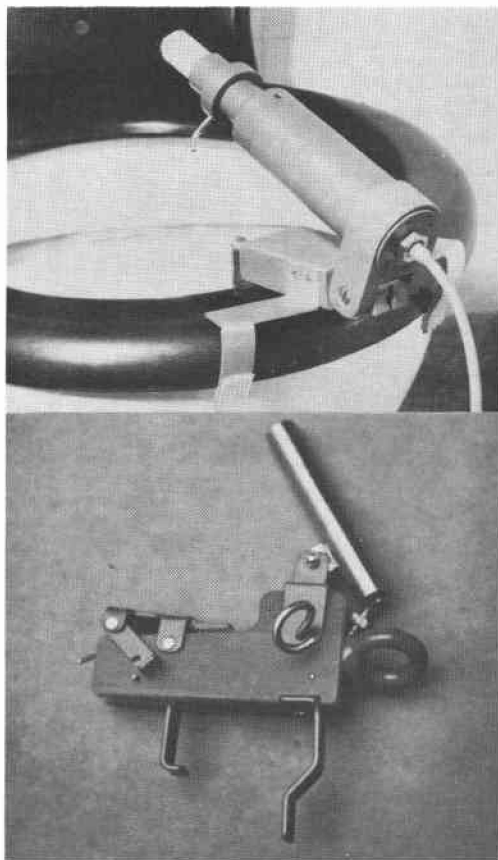


Fig. 11. Top, tampon insertion device developed in Muenster. Bottom, portable modification from the University of Heidelberg (see text).

Bilateral upper and lower limb involvement

Patients with quadrimemberal involvement have extreme difficulty in toileting. These patients need various devices for dressing and undressing, such as dressing sticks, wall hooks, etc. For perineal cleansing the bidet type of device is generally required. It is unfortunately not portable, and one must be obtained for each location that the child needs to do toileting.

The above survey of available aids is intended to serve as a working guide for therapists. These cases are fortunately rare, so no one has extensive experience and a continuing collection and dissemination of information on these devices would be of benefit to these patients.

Acknowledgements

The author is very grateful for the help that the sources mentioned have given in sharing their experiences and hope that anyone having a new device or method which proves successful will communicate with her for follow-up articles on the same subject.

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