

Continence Advisory Panel (CAP)

Position Paper

1. Background

Recent research revealed significant gaps in practice and challenges regarding levels and access to services and supplies related to (mainly urological) incontinence for the spinal cord injured/afflicted (SCI/SCA) person across public and private sectors of SA. This is most notable for essential long term care required after discharge, including annual check-ups, management of complications and access to supplies. While few centres may attempt to provide a “centralised” service via the integration of care, once discharged to the community, persons in need are encouraged to seek assistance via their local community clinic and medical practitioner, who are often not equipped or are unfamiliar with management of SCI related complications, and seldom, if ever, return to their original rehab unit.

This appears to be driven by a combination of factors, including lack of resources, expertise, lack of consensus regarding clinical practice, whether in public or private practice, disjointed supply chain infrastructure, and inconsistent reimbursement policies by various payers, be they Government, Road Accident Fund (RAF), Workmen’s Compensation Fund (COID) and/or private medical aid schemes (MAS). This appears to be underpinned by a general lack of awareness of patient rights to care by many stakeholders with respect to both access to care as well as obligations of the respective funders of benefits.

In South Africa no formal training program exists for spinal cord rehabilitation physicians, only the exposure one gets within certain specialties involved with rehabilitation of these patients. Consequently there is no integrated care model, least of all for those with permanent spinal cord injuries who are discharged to their communities to manage their own care.

2. Purpose

In response to these needs, the Continence Advisory Panel (CAP), under the auspices of the South African Spinal Cord Association (SASCA), has been created and intends positioning itself as a multidisciplinary interest/lobby group that will represent the scientific, educational, socioeconomic, ethical and professional interests of health care practitioners involved with and people living with bladder (and bowel) dysfunction associated with mainly SCI/SCA.

The concept of an advisory panel is well accepted world-wide and the CAP seeks to be an authority and knowledge resource for stakeholders in matters related to bladder (and bowel) management. This group intends to lobby other groups and government structures and funder community on reimbursement and their obligations to provide benefits. Critical to the sustainable success of the CAP will be multidisciplinary involvement and support from industry.

Introduction of new interventions is a constant in modern medicine. Medical practitioners practicing in this field require scientific evidence on net health outcomes before offering new procedures to

their patients. In addition, to meet clinical expectations of practicing specialists, these must stay consistent with fundamental medical and surgical principles. The CAP intends providing a pathway for review of such new interventions and as custodians of relevant guidelines and commentators on the standard of care based on best available evidence, will continuously strive to integrate these into current practice.

3. Vision

1. Establish the standard of care for people living with SCI/SCA specifically relating to continence who are wanting to lead an active and fulfilling life.
2. To improve access to continence care for Southern Africans through education, advocacy and service, thereby improving the standard of care, dignity and quality of life (QoL)

4. Mission

- Achieve optimal continence care by improving communication/advocacy regarding quality continence care pathways/guidelines and setting benchmarks through continuous engagement of all relevant stakeholders and standards development for SCI/SCA
- Develop and advance standards of care and guidelines for good clinical practice by dedicated multidisciplinary clinicians
- Improve public awareness by having accessible information (via the media), and linking with other similar organisations.

5. Aims and Objectives

The main aim of the CAP is to:

- Within a scientifically informed and collaborative environment, improve the quality of continence care for people with bladder (and bowel) dysfunction.

The objectives of the CAP are to:

- Understand and identify the needs of the constituents and beneficiaries of the CAP.
- Develop evidence/consensus-based management guidelines for good clinical practice
- Provide health care practitioner and consumer education and awareness through workshops and outreach programs.
- Promote advocacy and public awareness by developing fact sheets and linking with other similar consumer groups.
- Identify research gaps and facilitate relevant research projects related to the gaps
- Bring as many people/organisations as possible into contact with the CAP through engagement with key stakeholder groups/organisations to influence practice to improve quality of life.

To achieve the objectives CAP will endeavor to collaborate with key role players viz. academic sector, public health care managers and providers, private practitioners, corporate sector and health care funders. Five task teams have been set-up to develop activities related to each of the objectives.

6. Organisation:

An inaugural meeting was held in Johannesburg amongst interested health care practitioners, sponsored by QASA, under the wing of the South African Spinal Cord Association (SASCA) and independently facilitated, on 14th September, 2013.

It was decided that the CAP had a natural link with SASCA but needed the support of other associated Societies, such as the Urology Society, as well as greater/diverse representation. Dr François Theron was nominated as interim Chairperson, through his position as Chair of SASCA.

The intention is to elect an interim board and allocate portfolios so that work may continue

7. Projects/Priorities:

- Develop and maintain a database of relevant health care practitioners, facilities and beneficiaries.
- Investigate training and educational needs and oversee development and rollout of relevant training programs, for both health care practitioners and consumers.
- Form a corporate alliance that facilitates convergence of resources and improving access to care and supplies.
- Compile integrated bladder management guidelines relating to catheterisation techniques to improve bladder management, reduce complications and enhance quality of life.
- Collaborate with other professional societies in areas of common interest where this could lead to greater impact or cost effectiveness.

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