



Good Prostate Cancer Care – a specification of requirements

Adopted by the board of the Swedish Federation of Prostate Cancer Associations 2011-12-06

Organization:

The treatment of prostate cancer should, in the first place, be organized in special, quality-guaranteed/certified clinics with multi-professional teams and follow-up responsibility. Suggested population base: around 300 000.

Where these requirements cannot be met, prostate centres should be organized, manned by specialized nurses with follow-up duties and a right to refer patients to physicians and other experts.

Quality Requirements:

Early detection:

Early detection is crucial for the outcome. Reliable methods for general screening are still lacking. The PCA wants all men, aged 50 or more, to receive information about prostate cancer, the right to be tested and the unreliability of the method.

Waiting times:

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| - Referral to urologist | At the most 4 weeks until suggested appointment date. |
| - From test to answer | At the most 2 weeks until suggested appointment date. |
| - Until treatment decision | Shortest possible but adjusted to the patient's need for consideration. |

Information:

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| - Prior to PSA | Oral and the National Board of Health and Welfare's brochure |
| - When informed of cancer diagnosis | Oral (by the physician) and written (brochure), written information about the patient association. Start-up package. |
| - Prior to decision on type of treatment | Oral and written information about alternative treatments, side-effects, etc. |

Cancer diagnosis information:

To be given by a physician in the presence of a relative and a contact nurse. Follow-up appointment within 2 weeks, at the most.

Second opinion:

Unbiased information about the patient's right to a second opinion and practical prerequisites.

Participation/decision support:

The patient's decision on type of treatment should be based on a good understanding of the diagnosis and treatment alternatives. Support should be adjusted to the patient in question, considering his/her capabilities. The patient needs time to acquaint himself with facts and to come to terms with his/her reactions to the diagnosis. Repeated contacts may be necessary,

eye-to-eye or in organized groups. Where the care facilities are insufficient, the patient association may be approached. Cooperation is recommended.

Treatment plan:

A written treatment plan should be set up in connection with choice of treatment and should be signed by physician and patient. To be revised continuously.

Psychosocial support:

This refers to the support provided by care facilities in order that patients and relatives will understand, accept and face up to the cancer diagnosis. This need varies from person to person and can only be assessed after a professional intervention. The absence of observable signs of anxiety/depression is not enough to do without an investigation. Support to be provided individually and/or in a group. In case of abnormal crisis reactions, the patient should be referred to a specialist.

Rehabilitation:

To minimize side-effects of the treatments, the patient needs detailed information about the risks involved and information about suitable self-care measures. Whenever necessary, patients should be referred to almoner, psychologist, urological therapist, physiotherapist, sexologist. An offer of a course in rehabilitation should be extended, whenever possible.

Maximum cost protection:

Sexual problems are a common side-effect of active treatment. There is evidence that potency medicaments administered directly after treatment reduce side-effects such as erectile dysfunction. A requirement, though, is that these medicaments should be covered by the maximum cost protection regulation.

Continuity:

Prostate cancer patients should be assigned a personal, medical-care contact person who should be available and should follow the patient throughout the whole care process. This also applies to so-called curative treatment. If a transfer is necessary, this must then be carried out in person.

Late side-effects:

Active treatment results in side-effects, in many cases after a long time has elapsed, resulting in an impaired quality of life. The patient should receive information about possible consequences and have access to assistance that might be required.

Relapses:

It is up to the clinic in question to actively follow the patient up to ten years after treatment and to look out for signs of relapses and also to be prepared for later incidences.

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