

# Store Praksisdag – Region Sjælland - 2024

- Kommunikation og den nye kroniske patientgruppe – canceroverlevende.

***”Når lægen selv bliver syg  
- kan man lære noget af det?”***

(V. Christian Freitag – praktiserende læge i Holte Lægehus og tidl. formand for PLO)

12. marts 2024

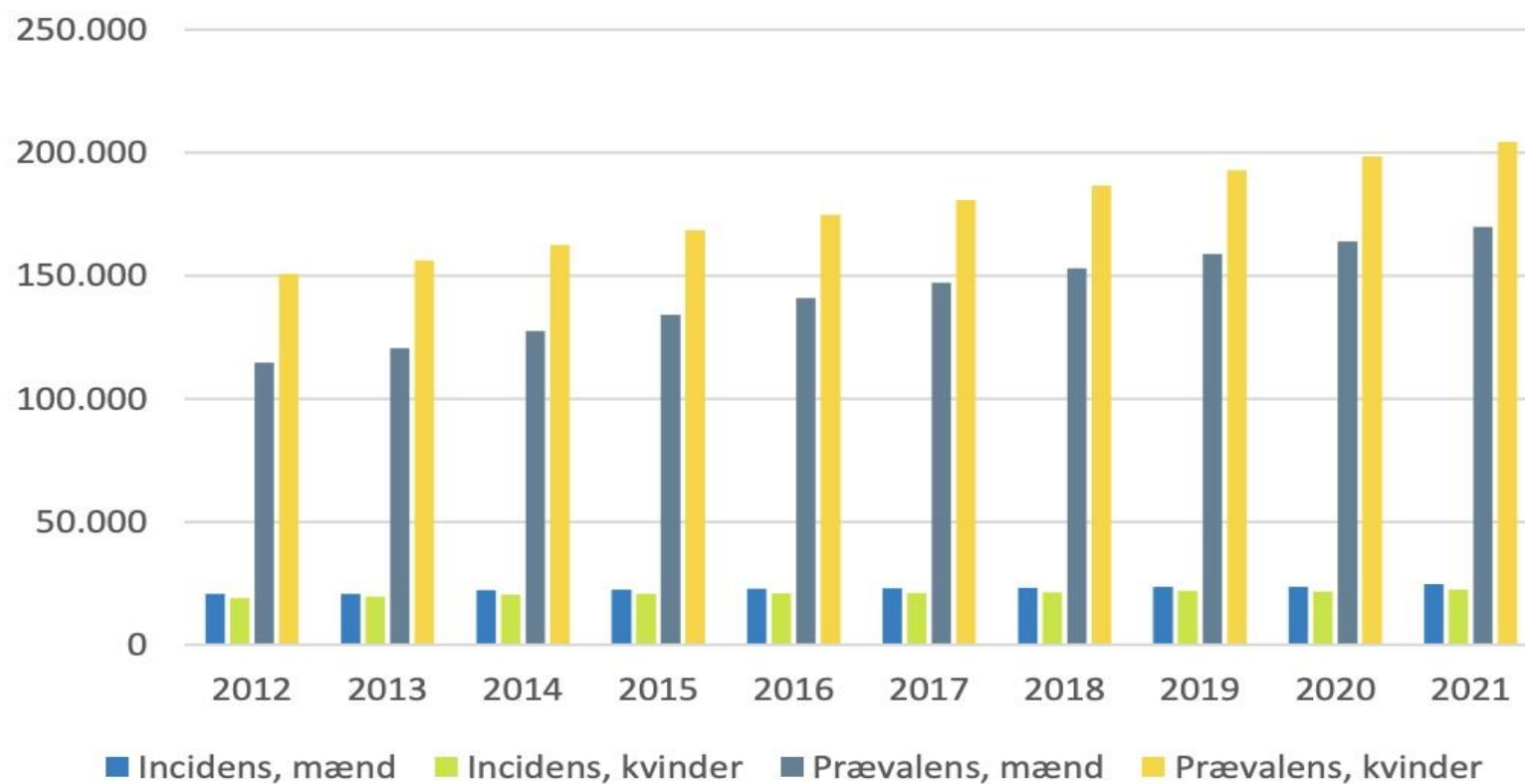
Comwell Køge

## Mit sygdomsforløb – i korte træk

- Januar 2021: Nogle hævede kirtler på halsen
- Februar: ØNH-læge, Ultralyd, Finnålsbiopsi (Normal – lavmalign kan ikke udelukkes”). Glandel-extirpation.
- Marts: Diagnose: ”Mantel Celle Lymfom”. Knoglemarvsbiopsi og PET-CT: Universel udbredelse (Knogler, lymfeknuder og milt).
- 18. marts: Diagnose om plan på Hæmatologisk afdeling.
- 23. marts – 15. juli: ”Maxi-CHOP” + ”Highdose Cytarabin” skiftende hver 3. uge + Rituximab
- April: Første kontakt til egen læge.
- 9. juli: PET-CT ”Helt uden tegn på cancer”
- 28./29. juli: Høst af stamceller
- 23. august: ”BEAM” (+fysplan og diætist)
- 30. august: Stamceller retur – Indlægges
- 7. september: Leuk: 0,1
- 10. september: Udskrives til restitution og efterbehandling (Rituximab hver 2. mdr i 3 år).
- 15. januar 2022 gradvis opstart på arbejdet

# Generel kræftopfølgning i almen praksis – nye tider.

Figur 12 Udviklingen i samlet prævalens og samlet incidens for mænd og kvinder, 2012-2021



Kilde: Cancerregisteret pr. 18. november 2022 og CPR pr. 18. november 2022, Sundhedsdatastyrelsen.

## Patienternes behov for opfølgning - Hvad ved vi om omfang og type?:

### Datagrundlag:

7.771 artikler, 300 artikler var relevante og 77 blev inkluderet i undersøgelsen af patienternes behov.

### Når jeg læser de artikler.....:

- "Hvilke USCN er der?" (Unmet Supportive Care Needs)
- "Kunne du godt tænke dig flere og bedre tilbud?"
- Alle artikler slutter med: *"Der er behov for yderligere undersøgelser...."*

# ”Unmet Supportive Care Needs”

**Table 3** Prominent needs lists of each domain

Domain of needs	List	Median Proportion (min–max)	
<b>Physical/ symptom</b>	• Lack of energy/tiredness	53.6% (10.6%-88.8%)	
	• Fatigue	51% (23%-87.7%)	
	• Pain	45.5% (18.5%-66%)	
	• Sleep disorder	44.9% (14%-57%)	
	• Hot flashes	43% (23%-100%)	
	• Osteoporosis/bone health	39% (37%-70.5%)	
	• Numbness/tingling in hands/feet	35% (11%-41%)	
	• Impairment of memory	33.1% (21%-48%)	
	• Change in appetite	32.4%	
	• Changes in weight	32% (10%-60%)	
	• Dry: vaginal dryness, dry/itchy skin, dry nose/mouth	29% (11%-30%)	
	• Manage side effects and complications of treatment	29.9% (3.5%-53.4%)	
	• Constipation	24.3% (21.7%-26%)	
	• Others: physical performance (39%), health problems regarding the breast (54%), reproductive system (58.2), urination changes (21%), and shortness of breath (21%)		
	<b>Psychosocial/emotional</b>	• Learning to feel in control of your situation	58.2% (47.9%-64.1%)
• Worry that the results of treatment are beyond your control		54.4% (16.7%-71.8%)	
• Concerns about the worries of those close to you		51.2% (43.4%-97.8%)	
• Keep a positive outlook		49% (37%-53.8%)	
• Anxiety		48.7% (16%-90.6%)	
• Feeling of uncertainty		46.2% (15.2%-92%)	
• Nervousness		44.6% (23%-66.1%)	
• Feeling down or depressed		44% (10%-82%)	
• Feelings about death and dying		42.2% (39%-68.4%)	
• Stress		35.6% (16.7%-77.5%)	
• Reassurance that the way you feel about your risk is normal		28.9%	
• Dealing with the loss of family members who had breast cancer		27.5%	
• Fears about physical disability or deterioration		26.9% (24%-42.4%)	
• Loss of interest in usual activities		24%	
• Dealing with feelings of isolation		22.4%	
<b>Fear of cancer recurrence/ spreading</b>	• Emotional support	25% (15.1%-80.3%)	
	• Changes to beliefs	4.5% (3.2%- 5.7%)	
	• Fears cancer spreading	57.5% (16.4%-80.3%)	
	• Fear of cancer recurrence	47.9% (28.6%-73%)	
	• Dealing with the impact that having a faulty gene has had on your family	41.3%	
	• Fear of further hospital stays	No data	
	<b>Family support</b>	• Help to know how to support my family/ partner	85.2%
		• Talking to other family members about having a faulty cancer protection gene	37.4%
		• Family or friends to be allowed with you in the hospital whenever you want	29.6%
		• Talking to your children about their cancer risk	28.8%

**Table 3** (continued)

Domain of needs	List	Median Proportion (min–max)
<b>Medical support</b>	• Ongoing medical service	63% (37.4%-74.5%)
	• Nutritional/diet needs	58% (28.4%-74%)
	• Wished to obtain medical service in a quick and easy way when in need	50.9% (43.7%-85.5%)
	• Reassurance by medical staff that the way you feel is normal	39.8% (30.8%-43%)
	• Hospital staff acknowledge, show sensitivity to your feeling and emotion needs	37% (28.2%-48.8%)
	• Hospital staff attending promptly to your physical needs	35.7% (27.3%-47%)
	• My doctors to talk to each other to coordinate my care	35.3% (9.6%-79.8%)
	• Being treated like a person not just another case	34.2% (25.6%-97.8%)
	• Feeling reassured that the best medical care is given	33.1% (9%-87.7%)
	• Being treated in a hospital/clinic that is as physically pleasant as possible	32.9% (14.9%-41.9%)
	• To feel I can manage my health together with my health team	15.6% (8.9%-85%)
	• Help to handle the topic of cancer in social/work situation	53.5% (50.4%-90.9%)
	• Financial strain/difficulties	26.2% (0.2%-48.5%)
	• Dealing with insurance issues that arise from having a faulty cancer protection gene	22.3%
	<b>Social support</b>	• Diminished sexual activity/sexual drive
• Changes in sexual relationship		33.3% (19%-35%)
• Change in sexual feeling		29% (25%-38.5%)
<b>Sex/intimacy</b>	• Help to make new relationships	94%
	• Help to deal with the impact of cancer on my relationships	84.6%
	• Help to make my life count	84.2%
	• Help to move on with my life	82.2%
	• Help to make decisions about my life in uncertain times	82.1%
	• Help to cope with others' expectations of me as a survivor	78.6%
	• Help with others not acknowledging the impact cancer has had on your life	60% (36.8%-83.2%)
	• Feeling unwell a lot of the time	51.3% (37%-97.8%)
	• Help to deal with my belief that nothing bad will happen again	41.5% (18.7%-87.2%)
	• Deciding how best to manage increased cancer risk	39.7%
	• Learning to feel in control of your situation	33%
	• Help manage household responsibility	31%
	• Adjust to changes in your life as a result of cancer	26.7%
	• Instrumental (practical) support	19.8% (7%-32.5%)
	<b>Daily activity</b>	• Exercise
• Physical activity to decrease the risk of recurrence or improve survival		55.6% (53.1%-63%)
• Yoga/meditation		55%
• Not being able to do the things you used to do		50% (29.1%-98.6%)
• Work around the home		44.9% (39.3%-59.8%)
<b>Spiritual support</b>	• Help with my spiritual beliefs	42% (40%-92%)

**Table 3** (continued)

Domain of needs	List	Median Proportion (min–max)
<b>Information support</b>	• Up to date understandable information about your cancer and treatment	62.5% (31.4%-89.5%)
	• Being informed about cancer that is under control or diminishing (i.e., remission)	55.3% (20.8%-76.5%)
	• Information related to hereditary disease	52.5% (52.1%-52.9%)
	• Being informed about the things you can do to help yourself to get well	51% (14.9%-80.9)
	• Being given explanations on those tests about which you would like to get explanations	47% (29.7%-92%)
	• Being informed about your test results as soon as feasible	44.9% (20.8%-59.8%)
	• Being given information (written information, diagrams, and drawings) about aspects of managing your illness and side effects at home	44.2% (18.8%-73.5%)
	• Being given written information about important aspects of your care	44.2% (31.9%-97.1%)
	• Being adequately informed about the benefits and side effects of therapy before you choose to have them	41.5% (24.8%-91.3%)
	• Information resources	33.6% (28.7%-38.5%)
	• Information relevant to my partner/family	32.5% (28.1%-92.7%)
	• To be given choices about when to go in for tests or treatment	30.3%
	• Obtain information to help manage increased cancer risk	29.7% (29.1%-34.7%)
	• More choice about which cancer specialists you see	29.3% (19.3%-45.3%)
	• Be given information about sexual relationship	27.8% (19%-33.3%)
• More choice about which hospital you attend	25.3% (21.4%-31.6%)	
<b>Medical counseling</b>	• Patient education: diet:19%, relaxation/meditation: 18%, physical activity: 10%	
	• To have one member of the hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up	45.5% (34.9%-87.7%)
	• Spent time discussing disease	45.3% (31.8%-63.2%)
	• Having access to professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if you, family, or friends need it	43.9% (27.7%-82%)
	• Spent time listening to feelings	31.5% (19.7%-43.2%)
<b>Peers communication</b>	• Counseling: psychologist or psychiatrist: 15.5% (15%-16%), financial and occupational: 15%	
	• To talk to others who have been through a similar experience	40.4% (29.6%-87%)
	• Talking with other women who have faulty cancer protection gene	36%
<b>Cognitive needs</b>	• Finding someone who understands your situation	32.3% (29.6%-35%)
	• Cognitive needs	37.8% (36%-39.5%)
	• Memory or concentration problems	10%
<b>Dignity</b>	• Help to adjust to changes in the way I feel about my body	82.1%
	• Body image perception	38.4% (8.9%-59.5%)

## KRÆFTRELATEREDE OMRÅDER

Recidivmistanke  
Alarmsymptomer  
og tegn på recidiv

Senfølger  
Fysiske  
Psykiske  
Sociale  
Eksistentielle

## GENERELLE OMRÅDER

Andre kroniske sygdomme  
Fysiske  
Psykiske

Forebyggelse  
Livsstil/egenomsorg  
Screening  
Vaccination

Rehabilitering  
Netværk

## Pointer, som jeg har lært – efter selv at have været patient:

- Cancer er jo ikke længere bare "Cancer" – det er en lang række meget forskellige sygdomme - Det skal også afspejle vores indsats.
- Mennesker reagerer meget forskelligt på diagnosen og behandlingen. Og især reagerer vi forskelligt efter behandlingsforløbet – Det bør også afspejle indsatsen fra almen praksis.
- Almen praksis er grundlæggende ret godt rustet til at hjælpe patienter med kræft, netop fordi vi er vant til meget forskellige sygdomme, forløb og patienter.
- Almen praksis skal **OG MÅ** ikke være kræftspecialister, men vi skal forstå hvor forskelligt kræft kan påvirke mennesker – og derfor kan vi hjælpe mange mennesker rigtig godt.
- Det vigtigste er ikke at finde noget du kan gøre, men at finde ud af, om du kan hjælpe denne patient nu, eller senere.
- Når man selv har mærket hvor meget helbredet og sundhedsvæsenet betyder, er det enormt bekræftende og tilfredsstillende selv at arbejde i det. Den oplevelse burde vi alle have – og så alligevel ikke....

