Summerschool Palliative Care

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When things go wrong - a tale of missed opportunities

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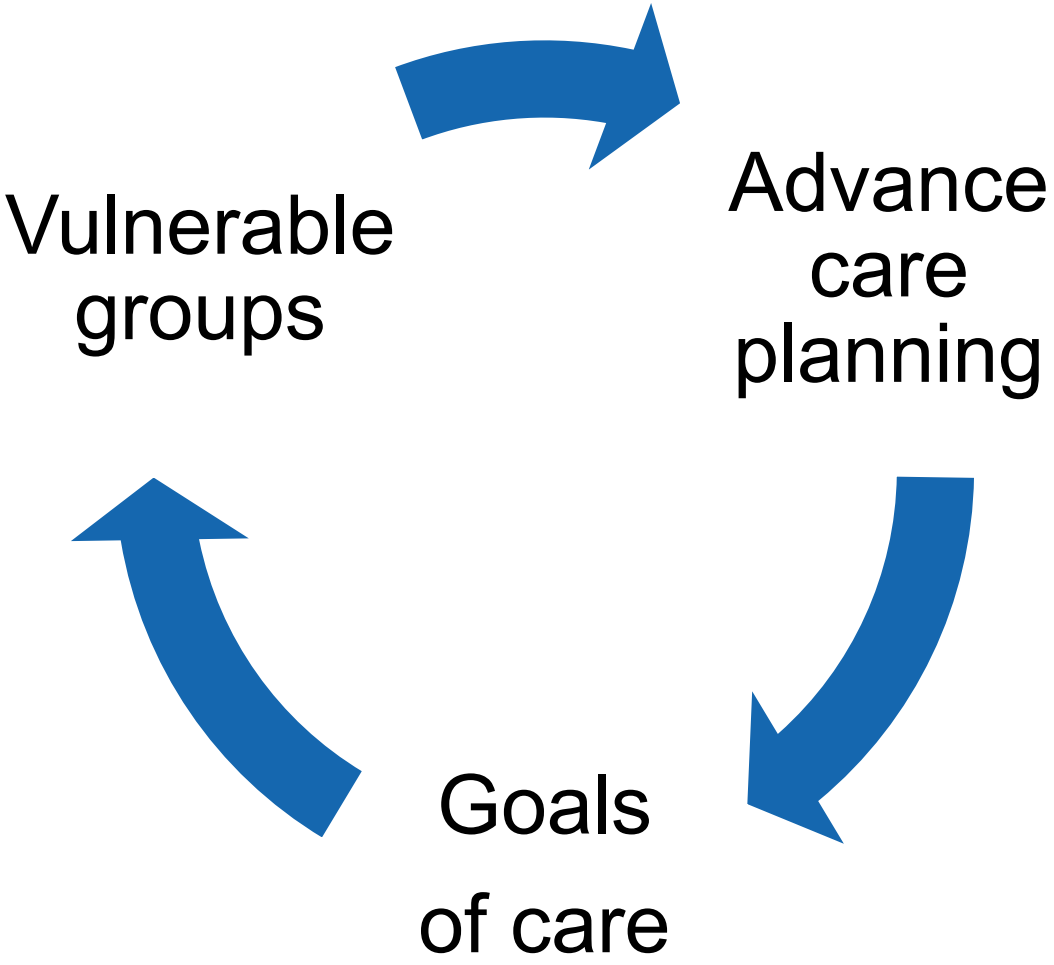
Mr. G.V., *1959



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Start of the tale

Referral from external physician /primary physician

Sehr geehrte Kolleginnen und Kollegen

Hiermit möchte ich Ihnen oben genannte Person zur **dringlichen ambulanten ORL-Abklärung** überweisen. Diagnosen siehe unten. Herr V. lebt im Pflegezentrum Rotacher und zeigt seit einigen Wochen eine zunehmende Schluckschmerzen und Dysphagie. **Nahrung und Speichel können teilweise nicht mehr gut geschluckt werden**. Zunehmende Schwäche und Gewichtsverlust von 6kg innert 6 Monaten. Fragestellung: Tumorrezidiv?

Diagnosis

- Suspected Hypopharynx Carcinoma cT4cN1cM0
  - Suspected secondary carcinoma DD pulmonary metastasis
  - Further Carcinomas
- St.n. CVI 1/2016 (left-sided hemiparesis)

Tumorboard recommendation:

- Bronchoscopy (biopsy of the pulmonary lesion)
- Planning of systemic treatment

First consultation

- Patient shows up accompagnied by a nurse from the nursing facility he lives in
- Severe and uninterrupted alcohol overuse
- Denies pain or dypnea – unable to report anything else by himself
- Some infomation by the nurse; no judgmental capacity according to the nurse

First consultation

- Brother of the patient is called during holidays

- Arztbericht:

«Es folgte eine telefonische Besprechung des Procederes mit dem Bruder und dessen Ehefrau. Die aktuelle Situation mit drohendem Erstickungstod in den nächsten Wochen wurde erläutert, ebenso die aktuelle onkologische Situation mit Verdacht auf zwei grossen, voneinander unabhängigen Karzinome mit insgesamt schlechter Prognose. Die Familie entscheidet sich klar für eine zeitnahe Tracheotomie. Im gleichen Eingriff werden wir den Hypopharynx biopsieren. Der Bruder ist aufgeklärt und einverstanden mit den Eingriff (telefonische Aufklärung). Gemäss Pflegerin sei der Stridor seit anfangs Mai bekannt und habe sich nicht wesentlich verändert.»

«Discussion on the phone about the next steps with the brother and the brothers wife. The situation – threatening death by asphyxiation within the next weeks – were explained, as well as the oncological situation with suspected carcinomas and bad prognosis. The family clearly opts for a timely tracheotomy. We will do a biopsy of the hypopharynx at the same time. The brother is informed and consents (phone information). According to the nurse, the stridor has been present since May (2 m)and has not change since.

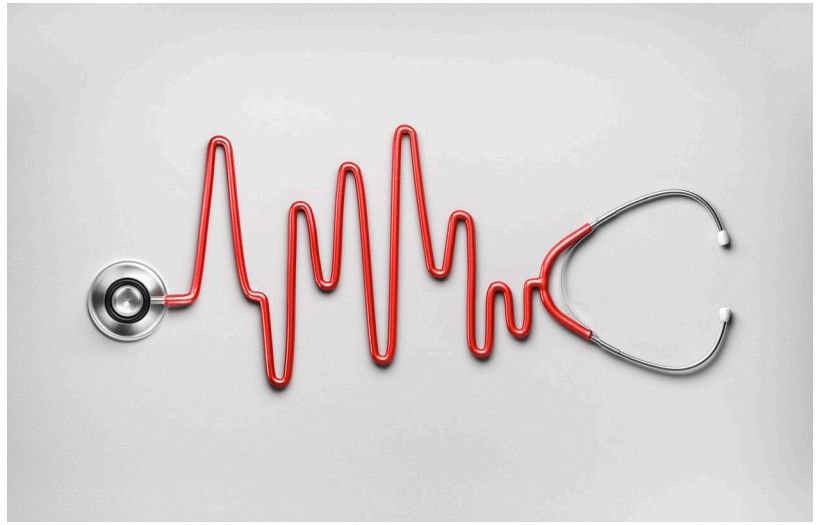
What happens next
D0

- Day 0: Same day anesthesia consultation

  «…starkes Giemen, Patient nicht compliant, Angehörige telephonisch aufgeklärt»
  «wheezing, patient not compliant, relatives informed by phone»

What happens next
D4

- Day 4:
  - Admission
  - Surgery – Tracheotomy
  - To normal ward



What happens next
D5

- Day 5:
  - «Delirious and agitated at night»
  - «Pulling on the canula cuff»
  - «Patient aspirates while eating»

What happens next
still D5

Second tumorboard :

- *«We recommend to redirect towards a palliative approach because of reduced status and dementia»*
- *«Cancel lung biopsy»*
- *«Refer to palliative care and evaluate PEG»*

No Palliative Care physician in this board

Note to file:

«Bei nicht urteilsfähigem Patienten telefonische Aufklärung der Ehefrau. Sie ist unter Kenntnisnahme der Risiken einverstanden mit der Einlage einer PRG.»

«Due to lack of judgmental capacity from the patient, the wife was informed via phone. She is ok with placing a gastric tube»

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What happens next
still D5

Day 5 - file:

- «Procedere»
  - *Palliative / best supportive care*
  - *Sitzwache / hospital sitter*
  - *Percutaneous gastrostomy planned (discussed by phone with brother)*

What happens next
still D5

- Day 5:
- «Procedere»
  - *«we called the palliative care team, but they pretend to have no available bed and also don't see the indication to take the patient from our ward to theirs»*

Redirection
D6

Day 6: Palliative Care bed available

- **S**ymptoms – SPI 11, ECOG4, disoriented, no communication, irritated by trach, scratching freshly placed PEG
- **E**ntscheidungsfindung – no advanced directives; brother informs that patient has been demented and bed-ridden for the longest time in the nursing home. Surrogate will by proxy: not fully clear but mainly «no suffering and no life-prolonging treatments»
- **N**etzwerk: nursing home, demented, bed-ridden, legal guardian (finances); brother
- **S**upport: unable to self-care; offer for psycho-oncology, spiritual care and music therapy on SPCU

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Palliative Care
D7

Day 7: Roundtable

- According to niece, quality of life has been bad the past years with alcohol misuse and beeing bed-ridden and not what the patient wanted

- Decision against antibiotics in case of aspiration
- Decision against heparine
- Decision against artificial nutrition

Palliative Care
D7-11

Day 7: Roundtable

- No life-prolonging measures
- Symptom control

Day 7-11:

- Morphin 1mg/h
- Midazolam 0.5mg/h
- Volunteers reading books in Italian

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Palliative Care
D11

"There's no easy way I can tell you this, so I'm sending you to someone who can."

Lessons learned

- Missed opportunity to discuss surrogate wishes before first consult (2 months stridor) - communication
- Missed opportunity to discuss possible advanced directives at first consult (4 days to surgery)
- Missed opportunity to weight all options („making comfortable vs will suffocate“) (informed consent - communication)
- Missed opportunity to „redirect and involve PC team“ instead of „getting rid of after PEG“ (PEG was never used!)

Thank you

"How a society treats its most vulnerable is always the measure of its humanity."

Statement by Ambassador Matthew Rycroft of the UK Mission to the UN at the Security Council Open Debate on Children and Armed Conflict

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