Cicely Saunders International
Better care at the end of life

WHO Collaborating Centre for Palliative Care & Older People

KING'S College LONDON

Advanced Liver Disease

The Oxford Advanced Pain and Symptom Management Courses 2019

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Nine years on…

- Numbers are still increasing
- Aetiology
- New models of care
  - emphasis on dual planning
- Increased awareness of best practice in prescribing
  - PCF
  - King's guidelines
- Increased recognition within the specialty

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What makes Liver Disease so special?

- Unpredictability
- Challenging symptoms often requiring admission to hospital
- Younger patients
- Maintaining hope
- Lack of evidence base; prognostication, symptom management and service configuration, although improving…

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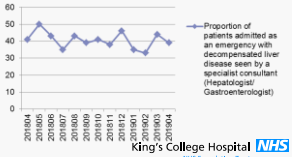
King's

- 80% of deaths within the liver unit occur in intensive care
  - 4-10 deaths per month

Emergency with decompensated liver disease seen by a specialist consultant



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Outline

- Facts and figures
- Identification – recap
- Models of care
- Management of advanced disease
  - Symptom prevalence
  - Complications
  - Prescribing – what's new?
- 'Shifting sands…'

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Chronic Liver Disease

- In the UK CLD now the fifth highest cause of mortality after heart, cancer, stroke and respiratory disease; only major cause of death increasing year on year
- In England 2% all deaths; 4% all deaths if any mention of liver disease included from death certification; 9000 deaths /yr England and Wales
- Disproportionately affects younger age groups; 40-49yr old age group ALD most common cause of death, 1 in 10 all deaths; 70% deaths occur in hospital. More likely to be from deprived background.

National End of Life Care Intelligence Network, Deaths from liver disease, implications for end of life care in England. March 2012

Volk ML et al. Hospital readmissions among patients with decompensated cirrhosis. Am J Gastro. 2011 Sept 20.

Verne J, Pring A. Raising the profile of end of life care needs for patients dying from liver disease –using national mortality data. Public Health England/ www.gov.uk/phe 2013

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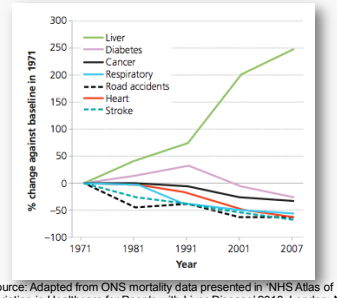
Chronic Liver Disease in the UK



Variable access to services

Variable quality…

Worldwide prevalence: 4.5-9%

Source: Adapted from ONS mortality data presented in 'NHS Atlas of Variation in Healthcare for People with Liver Disease' 2013. London: NHS Liver Care

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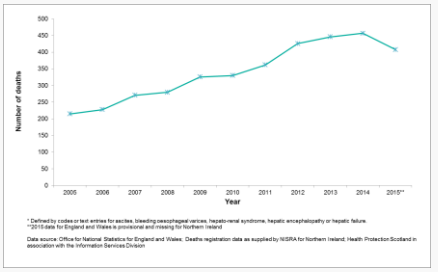
Impact of therapy on mortality HCV



Deaths from HCV or HCC in patients with HCV (PHE report on HCV 2016)

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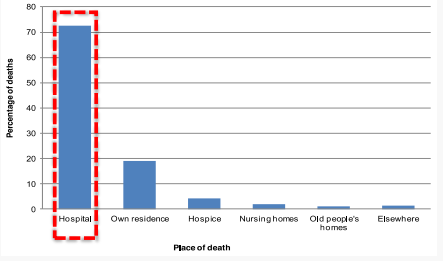
Place of death for patients dying of liver disease

Distribution of liver disease deaths by place of death, England 2001-2009



Source: Adapted from ONS data presented in "Deaths from Liver Disease", National End of Life Care Intelligence Network, London, 2012.

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HCC

Villanueva A. Hepatocellular Carcinoma. N Engl J Med 2019; 380:1450-1462

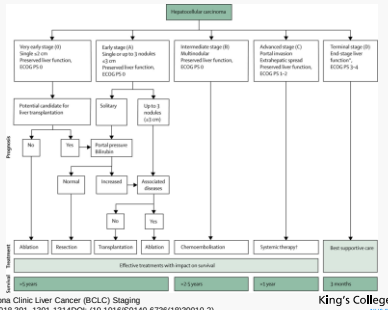

Fig 2: Barcelona Clinic Liver Cancer (BCLC) Staging
The Lancet 2018 391, 1301-1314DOI: (10.1016/S0140-6736(18)30010-2)

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Identification of advanced disease

- Synthetic and excretory function
  - INR > 2, albumin < 20mmol/l
  - Bilirubin > 100µmol/l
- Performance status over time
- De-compensation
- Child Pugh /MELD/UKELD score
- SPICT: PS↓, ≥2 unplanned hospital admissions in 6/12, wt↓,symptoms, LT CI

Medici V, Rossaro L, Wegelin JA, Kamboj A, Nakai J, Fisher K, Meyers F. The Utility of the Model for End-Stage Liver Disease Score: A reliable guide for liver transplant candidacy and, for select patients, simultaneous hospice referral. Liver Transplantation 2008;14: 1100-1106

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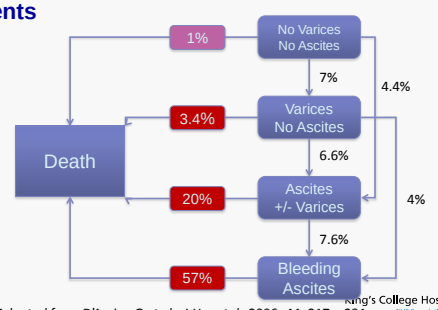
Child-Pugh score

Factor	Score of 1	Score of 2	Score of 3
Encephalopathy grade	None	1-2	3-4
Ascites	Absent	Mild	Moderate to severe
Bilirubin	<35micromol/l	36-60 micromol/l	>60 micromol/l
Albumin	>35g/l	28-35g/l	<28g/l
PT (secs prolonged) OR INR	1-4secs <1.7	4-6secs 1.7-2.3	>6secs >2.3
Child-Pugh score	**5-6 (A)**	**7-9 (B)**	**10-15 (C)**
Med. 1 yr survival **Med. 2 yr survival**	**95%** **90%**	**80%** **70%**	**45%** **38%**

NHS

Clinical course of cirrhosis: 1-year outcome probabilities according to clinical signs & events



Source: Adapted from D'Amico G et al. *J Hepatol.* 2006; 44: 217 – 231

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Proactive approach

- Increasing evidence that early palliative care intervention can improve symptom management and quality of life
  - Improved symptom burden and mood
  - Improved survival?
  - Less aggressive treatment and less hospitalization

- Greer JA et al. Early integration of palliative care services with standard oncology care for patients with advanced cancer. CA Cancer J Clin. 2013;63(5):349-63
- Temel JS et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N ENGL J Med. 2010:363(8):733-42
- Baumann AJ et al. Benefit of early palliative care intervention in End-Stage Liver Disease Patients awaiting liver transplantation. JPSM 2015:Dec 50(6);882-6 e2
- Walling AM et al. Impact of consideration of transplantation on end-of-life care for patients during a terminal hospitalization. Transplantation. 2013;95(4):641-6
- Early palliative care for adults with advanced cancer (Review) 2017 The Cochrane Collaboration

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Proactive approach

Hudson BE et al. Frontline Gastroenterology 2017;8:45-52

- Development and evaluation of a prognostic screening tool and supportive care intervention
- University Hospitals Bristol, UK
- Quality improvement process
- PDSA cycle;
  - Plan, Do, Study, Act

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Integration in practice

Hudson BE et al. Frontline Gastroenterology 2017;8:45-52

Screening criteria	Supportive care intervention
Childs Pugh C	Consultant led poor prognosis discussion
>2 liver related admissions in last 6 months	Poor prognosis letter to GP
Ongoing alcohol use in known ALD	Opportunity for advance care planning
Currently unsuitable for transplantation	Specialist palliative care review if complex symptomatic/social/psychological needs
WHO PS 3-4	Allocation of hepatology specialist nurse

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Proactive approach

- Advanced Chronic Liver Disease MDM
  - Likely to be mandated by NHS England
  - Poor prognostic criteria and management options as per Hudson paper
  - Evaluation of impact
    - Outcome measures – IPOS?
  - Costs: Evaluation of 13000 patients with cirrhosis in last year of life £7718/month/patient, spent 33% days in hospital and 52.5% re-admitted within 30 days of discharge. OP paracentesis services saved £4240 / patient

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Supportive care nurse

- Should we aim to identify patients earlier and intervene
  - who should intervene?
- Role of supportive care liver nurse specialist
  - Acceptable intervention, access to additional expert advice, support and continuity of care
  - Acceptable and feasible
  - Outcome measures: POS and EuroQol-5D-5L

Kimbell B et al. Palliative care for people with advanced liver disease: A feasibility trial of a supportive care liver nurse specialist. Pall Med. 2018, vol 32(5) 919-929

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Chronic Liver Disease

- Physical symptom burden
  - Complex and dramatic
  - Often require hospital admission
  - Poor evidence base with regard to pharmacology
- Psychosocial issues
  - Liver disease often associated with stigma
  - Complex socioeconomic background
  - Uncertainty; re-compensation, transplantation

Boyd K, Kimbell B, Murray S, Iredale J. Living and dying well with end stage liver disease: Time for palliative care? Hepatology vol. 55 (6), 1650-1651, June 2012

Morrison RS, Hope AA. Integrating palliative care with chronic liver disease. J of Pall Care 27:1/ 2011; 20-27

Mazzarelli C et al. Palliative Care in End- Stage Liver Disease: Time to do Better? Liver Transplantation 24 961-968, 2018 AASLD

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Living and dying with liver failure

Kimbell B, Kendall M, Boyd K, Murray S, 2013

- Serial interview study
  - 15 patients with advanced liver disease, 11 informal carers and 11 case-linked health / social care professionals, interviewed over a year
- High and prolonged burden of physical, psychological and social needs
- High level of information needs; poor understanding of liver disease
- Lack of continuity and holistic support

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What do patients experience?

- Scanty evidence, mainly in transplant pop.
- Pain – severe pain/opiate prescriptions are common as in advanced cancer [1,2]
- Fatigue – often profound [3]
- Sleep disturbance [4]
- Depression, anxiety (up to 50%) [5]
- Uncertainty / information need [6]
- Social isolation & stigma [7,8]

1. Rogal et al. *Dig Dis Sci.* 2013; 58(10):2276-85
2. Roth et al. *J Am Geriatr Soc.* 2000; 48(5): S122-30
3. Van der Plas et al. *Qual Life Res.* 2007; 16(3):375-8
4. Mostacci et al. *Neurol Sci.* 2008; 29: 237-
1. Bianchi et al. *Dig Liver Dis.* 2005; 37: 593-600
2. Bjork & Naden. *Nurs Ing.* 2008; 15: 289-98
3. Brown et al. *Qual Health Res.* 2006; 16: 119-36
4. Wainwright et al. *J Clin Nurs.* 1997; 6: 43-5

Symptom prevalence and QOL

Peng et al. Symptom prevalence and quality of life of patients with end-stage liver disease: A systematic review and meta-analysis. Pall Med 2019, vol. 33(1)24-36

- Systematic review and meta-analysis
  - 8 electronic databases (Jan 1980-June 2018)
  - 80 studies (30 SP, 41 QOL, 4 both)
    - Pain (30-70%), breathlessness (20-88%), muscle cramps (56-68%), sleep disturbance (insomnia 26-77%), psychological symptoms (depression 4.5-64%, anxiety 14-45%), erectile dysfunction prevalent in men (53-93%)
    - HRQoL patients with ESLD significantly impaired compared with healthy controls or patients with CLD

Refractory ascites

- Mortality of 50% at 6 months
- Transjugular intrahepatic portosystemic shunt
- Paracentesis
  - Risks of precipitating hepatorenal syndrome
  - Colloid volume expansion is probably unnecessary for safe withdrawal of < 5 L ascitic fluid
  - Implanted, externally draining peritoneal catheter
- Challenge regarding place of care

EASL. EASL clinical practice guidelines on the management of ascites, spontaneous bacterial peritonitis and hepatorenal syndrome in cirrhosis. J of Hepatol 2010 vol. 53:397-417

Runyon BA. Treatment of patients with cirrhosis and ascites. Sem Liver Dis 1997;17(3):249-260

Reisfield GM, Wilson GR. Management of intractable, cirrhotic ascites with an indwelling drainage catheter. J of Pall Med, 2003. Vol 6 (5): 787-791

Refractory ascites

- Co-ordinated care
  - Planned follow up by MDT in OP
  - Reduced readmissions, 12 month mortality & costs
- The alfapump® system
  - IP catheter connected to a subcut implanted battery powered device that moves fluid from peritoneal cavity & a 2nd that connects the pump to the urinary bladder
  - 2019 NICE – *not* approved for routine use 'serious and well recognised safety concerns'

Ge PS and Runyon BA. Care coordination for patients with cirrhosis: a 'win-win' solution for patients, caregivers, providers, and healthcare expenditures. J Hepatol 2013 vol 59. 203-204

https://www.nice.org.uk/guidance/IPG631Nov18

Implantable tunnelled catheters

- NICE approval in malignant setting
- Established guidance in place at King's but variable use
- REDUCe (Reduced Drainage Untreatable Cirrhosis) trial – feasibility study completed
- Anecdotal use across UK

Macklan L. Palliative long-term abdominal drains versus repeated drainage in individuals with untreatable ascites due to advanced cirrhosis: study protocol for feasibility randonmised controlled trail. BMC Open Access 2018 19:401

Spontaneous Bacterial Peritonitis

- Patients with SBP have an in hospital mortality of 20%
- Cumulative recurrence rates are 70%, median survival of nine months
- Prophylaxis
  - If suffered recurrent episodes then long term antibiotics may be appropriate
  - Norfloxacin / Ciprofloxacin recommended
  - NB antibiotic induced complications

Variceal bleeding

- Mortality from first presentation variceal bleed is about 50%, although influenced by severity of underlying liver disease
- Crisis planning, patient preferences
- Child-Pugh class, one year mortality rates from subsequent variceal haemorrhage:
  - A 5%
  - B 25%
  - C 50%

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Encephalopathy

- Metabolically induced, potentially reversible, functional disturbance of brain
  - Severe intrinsic hepatic dysfunction
  - Portosystemic shunts leading to the diversion of portal blood to the systemic circulation before removal of toxic intestinal substances
- Personality changes, impaired intellect, disturbed sleep pattern and depressed level of consciousness
- Marker of decompensation

Cash WJ et al. Current concepts in the assessment and treatment of Hepatic Encephalopathy. QJMed 2010; 103:9-16

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Prescribing in liver disease: key points

- Little evidence to guide practice; there is little information to guide drug dosing
- Liver has a huge reserve and damaged significantly before it starts to have an effect
- Unpredictable and each patient needs to be treated as an individual
  - Function of the heterogeneous pathophysiology of liver disease with respect to hepatocellular function, protein binding and hepatic blood flow
  - Aetiology may have an impact on how drugs are affected

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Drug handling in liver disease

- Patient factors
  - Diagnosis and signs and symptoms of liver disease
  - LFTs (trends not in isolation); markers of synthetic function
- Drug factors
  - Pharmacokinetic properties
    - Bioavailability, vol. of distribution, clearance
  - Pharmacodynamic properties
    - Relationship between drug conc. and response
  - Side effect profile and therapeutic index
  - Route of administration

North-Lewis P (ed). Drugs and the Liver. Pharmaceutical Press, 2008
Hanna M. The effects of liver impairment on opioids used to relieve pain in cancer patients. Pall Med 2011 25(5) 604-605

PCF6+ 2019

- Drug induced hepatotoxicity: intrinsic vs. idiosyncratic
- Pharmacological impact of hepatic impairment
  - Pharmacokinetic
  - Pharmacodynamic
  - Secondary phenomena necessitating extra caution
    - Ascites, coagulopathy, disruption of blood-brain barrier, encephalopathy, QT prolongation, renal impairment
- 'Safer drugs'
  - High PO bio-availability, min hepatic metabolism, low-moderate protein-binding, short half life, no sedative, constipating or hepatotoxic effects

PCF6+

- 'Generally safer'
- 'Use cautiously'
- 'Avoid if possible'

Non-opioids

- Paracetamol
  - 'Safe' for the majority of patients with liver disease
  - Oral administration at normal doses for **short** periods
  - **But** consider reduction in dose (2g/24hr) if prolonged therapy or malnourished (<50kg), chronic alcoholism, dehydration (glutathione depletion)
    - PO/PR 500mg q8h; maximum 1g q8h
  - Anecdotal experience from King's/liver units: IV paracetamol should be given tds (but contraindicated by manufacturers in severe impairment)
- NSAIDs
  - Risks outweigh any benefits
  - If unavoidable; ibuprofen PO 200mg tds

Weak opioids

- Codeine and dihydrocodeine
  - Extensive liver metabolism - active metabolites
  - Dihydrocodeine preferred due to PK profile
- Tramadol
  - Extensive liver metabolism - predominantly one active metabolite (O-demethyl-tramadol)
  - 90% renal elimination
  - Product literature reports significant increase in t1/2
  - Adverse effects, inc. lowering of seizure threshold
  - If renal and liver impairment or severe liver disease reduce frequency to bd or tds
- For all groups – generally avoid
  - If unavoidable start at lowest dose possible

Opioids

- Limited studies - many single dose
- Half life variable (range approx 2-5hrs)
- Most opioids undergo extensive liver metabolism and produce active metabolites, major metabolic pathway is oxidation, exceptions are morphine and buprenorphine which undergo glucuronidation
- No. of confounding factors make it difficult to predict pharmacokinetics in liver disease
- Pharmacodynamics - alteration end organ sensitivity
- Adverse effects - constipation and sedation
- Increased risk of toxicity with all opioids

Tegeder I et al. Pharmacokinetics of opioids in liver disease. Clin Pharmacokinetics. 37(1):17-40, 1999 Jul

Opioid analgesics

Rhee C, Broadbent AM. Palliation and Liver Failure: Palliative Medications Dosage Guidelines. JPM 2007,vol 10, no. 3:677-685

Drug	T1/2 Normal	T1/2 Cirrhosis	T1/2 CP-A	T1/2 CP-B	T1/2 CP-C
Fentanyl	263min	304min			
Morphine (IV)	100min 1.7hrs	121min 4.2hrs	123.4min 3.4hrs	110min 4.35hrs	 4.47hrs
Morphine (o)	3.3hrs	5.5hrs	6.4hrs	6.85hrs	4.4hrs
Morphine SR	4.01hrs	No data	7.36hrs		
Oxycodone	3.4hrs (after transplant)	13.9hrs (before transplant)			
Methadone	18.8hrs	No data	11.3hrs	13hrs	35.5hrs

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Alfentanil and Fentanyl

Alfentanil

Moderate hepatic extraction ratio & lesser volume of distribution:

•Reduced enzyme activity as in cirrhosis and hepatitis – marked impact

•Liver blood flow changes – enterohepatic circulation

•Protein changes – major impact: less deep tissue depots 'buffer' free amount in plasma and reduce plasma fluctuations, and relative decrease in protein binding at higher doses

Fentanyl

High hepatic extraction ratio & greater volume of distribution:

•Reduced enzyme activity as in cirrhosis – little impact

•Liver blood flow changes – only makes a difference in severe liver disease and little impact

•Protein changes – limited impact: deep tissue depots 'buffer' free amount in plasma and reduce plasma fluctuations

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Opioid analgesics

- No 'ideal' opioid
  - Fentanyl for those with hepatorenal syndrome
  - Morphine and buprenorphine (glucuronidation)
- For any opioid
  - Start at the lowest dose possible
  - Carefully titrate monitoring clinical response and adverse effects, particularly constipation
  - Avoid controlled release preparations and opioids with long half lives
  - Consider increasing the dose interval

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Antidepressants

- Most antidpressants are highly protein bound and hepatically metabolised by one or more CYP450 enzymes; metabolism further impaired in constitutionally poor metabolisers and risk of toxicity increased from a pharmacokinetic drug-drug interaction involving an inhibitor of the CYP450 enzyme
- Long half lives increase the risk of accumulation and side effects often an issue

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Antidepressants

- TCAs not first line treatment for depression
  - Amitriptyline, half life is long but unaltered
- All SSRIs accumulate in severe impairment
- 'Use cautiously'
  - Amitriptyline PO: 5-10mg nocte
  - Citalopram (unless additional risk factors for QT prolongation or severe cholestasis) PO 10mg od
  - Mirtazepine (lower risk of bleeding than SSRI) PO 15mg nocte
- 'Avoid if possible'
  - Sertraline unless for cholestatic pruritus

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Antiemetics

- Prokinetics
  - Domperidone used first line, extensively metabolised by liver therefore dose reduce by 50% (risk prolonged QT)
  - Metoclopramide, clearance rate reduced in cirrhotic patients therefore dose reduce by 50%
- 5HT3 receptor antagonists
  - Ondansetron reduced doses (constipating)
- Centrally acting antiemetics
  - 'Avoid if possible'
  - If unavoidable – reduced dose cyclizine, haloperidol and levomepromazine

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Anti-epileptics

- A number of pharmacokinetic changes impact on many of the anti-epileptics used in PC, sedative effects may also worsen or mask encephalopathy
- 'Generally safer'
  - Levetiracetam - dose reduction required if renal impairment (PO/IV: 250mg bd)
  - Gabapentin - anti-epileptic or for neuropathic pain, dose reduction if renal impairment (PO: 100mg nocte, increase by 100mg/24hr every 2-3 days)
  - Pregabalin - anti-epileptic or for neuropathic pain, dose reduction if renal impairment (PO: 25-50mg bd)

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Antipsychotics

- Limited data available
  - Many are highly protein bound
  - Many are extensively metabolised in the liver and dependant on one or more of CYP3A4, CYP2D6 and CYP1A2
  - Risks of prolongation QT – lowest for quetiapine
- Long term use should generally be avoided
- 'Use cautiously'
  - Quetiapine for psychosis PO: 12.5mg bd

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Benzodiazepines and Z-drugs

- Extensive liver metabolism - active metabolites
- Generally avoid unless in last days of life, or use for short term only
- Short acting benzodiazepines can be considered if clinically indicated
  - 'Use cautiously'
    - trial of lorazepam as anxiolytic, also used short term to manage alcohol withdrawal
    - trial of zopiclone as night sedative
  - Midazolam appropriate to use in last days of life
- Longer acting benzodiazepines may be used but dose and dosage interval should be altered

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Miscellaneous

- Antifungals
  - Fluconazole use with caution, 50mg od 7 days, avoid concominent use with fentanyl as CYP3A4 inhibition by fluconazole can result in accumulation
- Acid suppressants
  - PPIs in cirrhosis, limit use to specific indications, concerns re; poorer outcomes
  - Ranitidine – dose reduce renal impairment
- Antidiarrhoeals, antimuscarinics, bisphosphonates and denosumab, skeletal muscle relaxants, octreotide
- Systemic corticosteroids

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Pragmatism

- Assess each individual case
- Patients are often symptomatic
- Any drug prescribed should be used with caution and regularly reviewed
  - 'start low, go slow'
- Patients often have a fluctuating condition
- Overall goals of care need to always be considered
- Simplify long term hepatic drugs

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King's guidelines / PCF6+

- Updated guidelines 2018
  - New evidence relating to use of fentanyl in high doses / continuous infusions
  - Clobazam added
  - Antidepressants – Citalapram / Mirtazepine – both with caution
  - Section on oral candidiasis added
  - Debate relating to recommended dose of paracetamol
- Palliative Care Formulary 2019

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Psychosocial issues

- Prior coping strategies
  - Alcohol, drug use
  - Stigma associated with liver disease, hep B and C
- Complex treatment strategies
- Safeguarding issues
  - Fluctuating cognition - Role of advance care planning
- Carer stress
- Psychosocial issues relating to transplantation
  - Expectation vs. reality
  - Family dynamics esp. in relation to live related donation

Marie Curie, St Mungos (2011) Supporting homeless people with advanced liver disease approaching the end of life
Kalaitzakis E, Josefsson A, Bjornsson E. Psychological distress in patients with liver cirrhosis. Gastroenterology 2008; 134(4):A625-A25
Hansen L et al. Background and design of the symptom burden in end-stage liver disease patient-caregiver dyad study. Res Nurs Health. 2017;1-16

Advance care planning

- In anticipation of the potential fluctuation in capacity associated with encephalopathy it is vital that clinicians engage patients early in advance care planning
  - Exploration of values and goals
  - Advance care planning documentation
  - Review of experience as disease progresses
- Sharing of information across all care settings
- What do patients really think of this approach and what do they really want?

Advance care planning

Hudson B et al. The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview stdy of patients and bereaved carers. Pall Med 2018

- Qualitative study – semistructured interviews analysed using thematic analysis; 17 participants
- Described escalating physical, psychological and social needs as disease progressed, disabling symptoms, emotional distress and uncertainty, addiction, financial hardship and social isolation
- End of life care needs were incompatible with the healthcare services available to address them; attitudes towards palliative care were mixed, however participants valued opportunities to express future care preferences and an increased focus on symptom control and logistical aspects of care

Transplantation

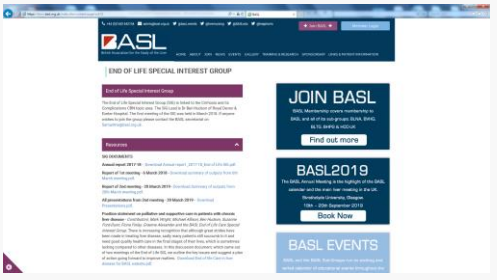
- Liver transplantation has become gold standard treatment for advanced chronic liver disease and fulminant hepatic failure
- 1 yr survival 80-90%, 5 yr survival 60-80%
- Yet approx. 50% of those assessed for transplant are declined and 20% of patients on the active waiting list will die
- Four people die for every one transplanted

Transplantation

Potentially treatable yet often fatal illness

- Significant symptom burden as disease progresses
- Resource allocation
- Maintaining hope
  - Remaining listed vs. pure palliation; psychosocial support
  - 'ongoing presence' and 'non abandonment'
- Should we re-consider including a palliative care assessment within the assessment process?

Larson AM, Randall Curtis J. Integrating palliative care for liver transplant candidates: "Too well for transplant, too sick for life" JAMA 2006;295(18):2168-2176
Gott M et al. Transitions to palliative care in acute hospitals in England: qualitative study. BMJ 2011;342:d1773



IQILS

Two levels of accreditation: level 1 – QI plan in place, level 2 external review and accreditation

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Challenges and opportunities

- Incidence and prevalence of chronic liver disease is set to increase
- Patients often have a high symptom burden requiring complex and often acute management but often not referred for palliative care
- Little evidence to guide practice but increasing
- Paradox of potentially life saving options for treatment in the context of a fatal disease
- Current service provision doesn't meet need, but changing…

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