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Clinical Care for ME/CFS

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Disclosures

Vortragshonorare:

Grünenthal
Sandoz
Pfizer
Almirall

Ärztlicher Beirat:

WE&ME Foundation

Context

- Neurology practice outside hospital/university
- ~1000-1500 patients for evaluation for ME/CFS in the last 7 years
- Long-term follow-up in many cases
- My personal bias – the patients that I see…
  - …usually have had symptoms for several months
  - …mostly have had thorough evaluation (including psychiatric)
  - …mostly have had different treatment trials (including rehab, psychiatric)

Approach to diagnosis

- Evaluate for Post Exertional Malaise (history, DSQ-PEM, hand grip testing)
- Evaluate for differential diagnoses (i.e. neuromuscular)
- Evaluate for comorbidities
- Evaluate further diagnostics

Approach to diagnostics

- Chronic illness is expensive!
- I order costly tests only if they might lead to treatment trials, i.e.
  - Viral reactivation
  - Microclots
- Diagnostic testing with consideration of PEM

Approach to pacing

- Individual approach
- Regularly ask „what happens after activity“ – this might change in the disease course
- Regularly explain the concept of pacing
- Look for „rolling PEM“
- Talk about psychological issues/frustration that go along with the need for pacing

Approach to comorbidities

- Comorbidities don't equal ME/CFS but offer a chance of treatment

- Common comorbidities and potential tests
  - Dysautonomia/POTS: NASA Lean Test, COMPASS31, dysautonomia testing
  - Small Fiber Neuropathy: sensory – thermal, SFN-SIQ, QST, Sudoscan, skin biopsy
  - Mast Cell Activation (Syndrome): Tryptase, Leukotrienes, CD117, treatment trial
  - Immunedeficiencies: MBL, IgG-Subclasses, etc
  - Hypermobility: clinical evaluation, genetic testing
  - Psychological: evaluation by experienced clinician

Approach to comorbidities

Treatment options for comorbidities:

- Orthostatic: non-medication (fluids, salt, etc) and medication (ivabradine, midodrine, etc)
- Mast Cell Activation: antihistamines, mast cell stabilizers, etc
- Dysautonomia: pyridostigmine, transcutaneous vagus stimulation, breathing techniques, etc
- IgG-Subclass deficiency: IvIg
- SFN: IvIg
- Hypermobility: specialised physiotherapy
- Psychological: adapted psychotherapy, medication with added anti-inflammatory effect

Approach to off-label treatments

- There is no approved treatment for ME/CFS
- However, there are several off-label medications in frequent clinical use
- Usually only very limited, mainly observational, evidence
- When used, one needs to be especially critical of effect/tolerability
- Documentation and proper pre-treatment patient information are essential

Approach to off-label treatments

- If not ce
- Step by
- If there eatments
- Aim of t
- Cheap d

Medikament/Medikamentenklasse	in Anspruch genommen von (%)	Zustandsverbesserung keine (%)	phasen-weise (%)	dauerhaft (%)
Immunglobuline (subkutan/intravenös)	10,92	57,33	24,00	18,67
Antihistaminika/Mastzellstabilisatoren	59,24	51,84	32,19	15,97
Antibiotika	38,57	69,81	18,49	11,70
Virostatika	15,87	66,06	25,69	8,26
Cholinesterasehemmer	14,41	62,63	23,23	14,14
Antikonvulsiva	15,87	56,88	29,36	13,76
Beta-Blocker	27,51	43,92	26,98	29,10
IF-Kanal Hemmer	12,95	31,46	29,21	39,33
Low-dose Naltrexon	26,06	45,25	32,96	21,79
Low-dose Aripiprazol	18,20	53,60	22,40	24,00
Saure Nichtopioid-Analgetika	71,47	60,49	37,08	2,44
Nichtsaure Nichtopioid-Analgetika	37,55	63,18	35,27	1,55
Serotonin-Antagonist-und-Wiederaufnahmehemmer	19,65	67,41	21,48	11,11
Noradrenalin-Wiederaufnahmehemmer	5,10	71,43	25,71	2,86

[1] *Hainzl A et al. (o.12091630*

Approach to social issues

- Documentation of functional impairments (ADL, IADL)
- Use of FUNCAP55
- Evaluation of i.e. wheelchair, adapted housing
- Evaluation of care assistance – especially relevant in Severe ME

Conclusions

- There are off-label drugs that can have a positive effect in ME/CFS
- There are comorbidities that can offer a pathway to treatment
- Small effects can make a big difference in quality of life
- Diagnostics and treatments with consideration of PEM and cost

On-Demand Courses

https://mecfs.at/on-demand-fortbildungen/

ME/CFS Biobank

Home › Forschung › Projekte › Computer-based Clustering of Chronic Fatigue Syndrome Patients › ME/CFS Biobank Austria

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Was ist der Zweck dieser Biobanksammlung?

Thank you for your attention!

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