Sussex MND Network Stakeholder day

Tuesday 7th November 2023

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Sussex MND Care & Research Network

MND Clinic

NHS
University Hospitals Sussex
NHS Foundation Trust

What do we offer?

- Specialist neurology clinic
- Neurologist & Network coordinator, 1 hour appointment new patients.
- Second opinion on diagnosis
- Discuss research opportunities
- Genetics discussions
- Coordinate care
- Advice to community teams
- Botox
- Cognitive screening assessment

Who do we see?

- Around 60 new patients a year, follow up to around 50-60% local patients.
- Patients from across Sussex & Kent & Surrey borders.

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The Louisa Martindale
Building
NHS


NHS
University Hospitals Sussex
NHS Foundation Trust

Patient feedback

It was all explained thoroughly. Dr was exceptional; friendly, helpful, knowledgeable, kind.

It all went very well.

Appreciated the attention & feedback, I sense there is clinical support for one in my condition

Both were very kind and understanding

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Future service developments:

- Expand Coordinator role.
- Psychology.
- Include other specialist disciplines (e.g. respiratory, psychology, palliative care).

MND Network objectives 2021-24

1: To ensure access to specialist non-invasive ventilation services close to the person's home.

2: To improve the identification of and support for cognitive and emotional/psychological difficulties.

3: To work with local stakeholders and MND Association colleagues to both establish new and support existing MND Specialist practitioner posts.

4: To explore and confirm the new structures through which MND network services will be delivered across Sussex.

5: To ensure continued access for PABMND to research across Sussex.

6: To establish and sustain an MND Network patient and public involvement group.

7: To develop a tool to measure the impact of services on the well-being and quality of life of people with MND.

8: To integrate new ways of working into MND care, including through the use of technology. https://sheffieldmndcarecentre.sites.sheffield.ac.uk/about-mnd/remote-health-monitoring

9: To audit MND care.

10: To facilitate, develop and deliver education sessions to HSCPs across Sussex.

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2: To improve the identification of and support for cognitive and emotional/psychological difficulties.

- Achievements:
  - Identifying gaps and capturing demand
  - Counselling
  - Art Therapy
  - MiND toolkit feasibility study
- Future plans:
  - Increase cognitive screening in MND clinic.
  - Psychology post

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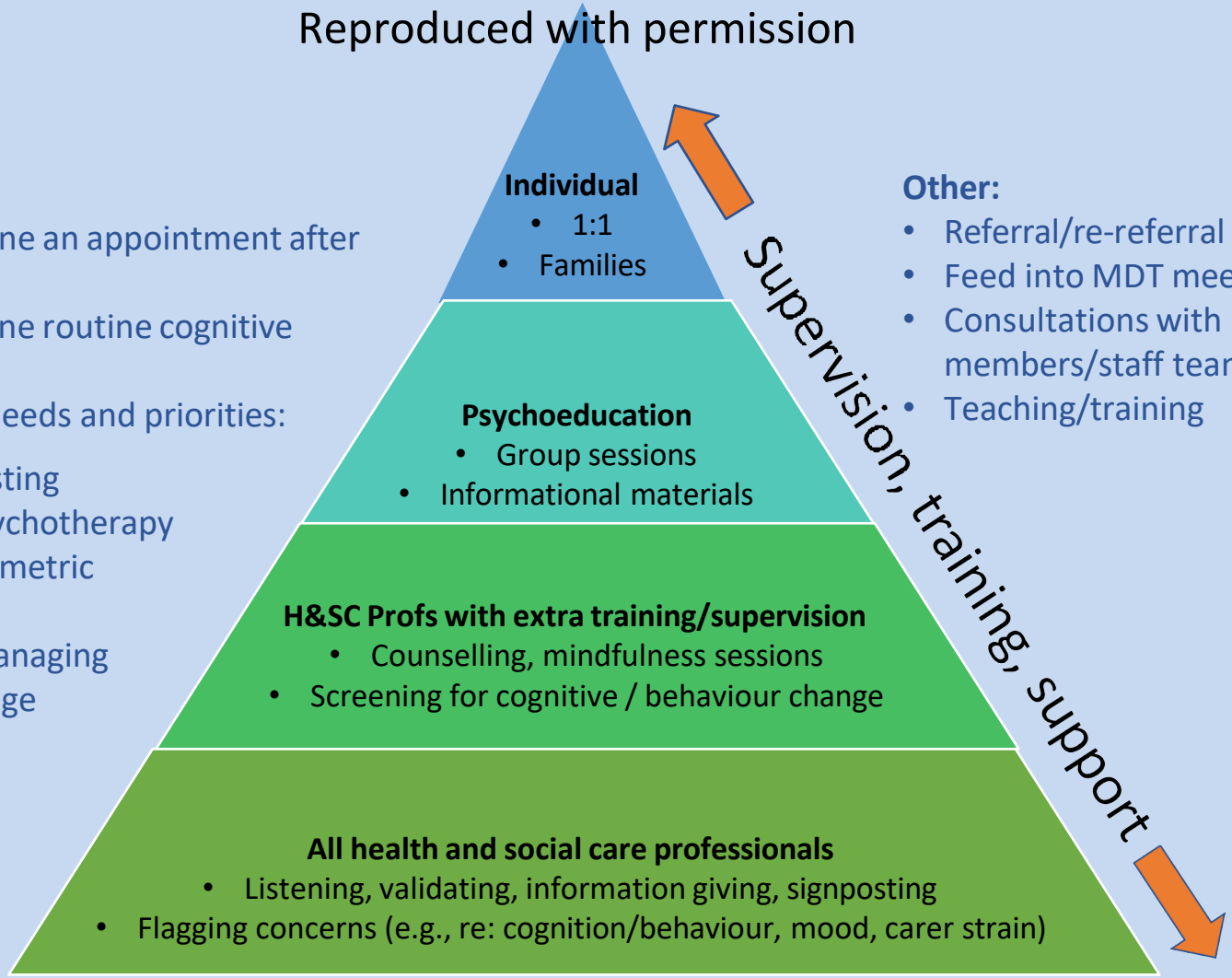
Model of care: Sheffield MND care centre: model of psychological support
Reproduced with permission

Routine:

- Offering everyone an appointment after diagnosis
- Offering everyone routine cognitive screening
- Depending on needs and priorities:
- advice / signposting
- time limited psychotherapy
- detailed psychometric assessment
- support with managing cog/behav change



Other:

- Referral/re-referral at any stage
- Feed into MDT meetings
- Consultations with individual staff members/staff teams, joint work
- Teaching/training

Objectives 2024-2028

Some proposed areas for our next grant:

1. Respiratory ventilation services- tables 1&2
2. Emotional and psychological support-tables 3&4
3. Gastrostomy –tables 5&6
4. Genetics-tables 7&8

There are 2 tables assigned to each of these themes

- **Spend 15 minutes in your group- discussing the prompt questions.**
- **You will then be prompted to move to second topic**

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Network Objectives discussion

Spend 15 minutes discussing in groups, make notes on flip chart. Choose someone from group to feedback

Prompt questions:

1. What are the current challenges/issues?
2. What works well already e.g. in your area?
3. What else can you suggest to make it better?

Think about all aspects, e.g: patient care, service capacity issues, professional skills/knowledge

Scenario 1

Ruth

- Ruth is a 52 year old lady diagnosed with MND in October 2022, following a 9 month history of upper limb weakness. Presented with upper limb onset but the disease has spread to her lower limbs and bulbar area quite quickly.
- Ruth has always been quite open to conversations but from the beginning has said she doesn't want to know too much at one time and will deal with issues as they arise. Hasn't wanted to discuss advance planning or life prolonging interventions.

- October 2023 - Speech only just intelligible and swallow deteriorating. Weight currently stable.
- Now is the time to have a PEG inserted if this is what she chooses. A delay in making a decision about this procedure has already led to one admission for dehydration, as well as anxiety around swallow / eating and drinking.

Scenario 2

Audrey

- Audrey is an 80 year old woman diagnosed with MND in Dec 2022 during a hospital admission while living in another area.
- Moved approximately 3 months ago to be with daughter locally but has had no contact with local services, including GP.
- Admitted to hospital in respiratory failure, now on an acute respiratory ward. Now trialling NIV again after not using it at home.
- Appears to have cognitive impairment, doesn't accept diagnosis of MND.
- Eating and drinking small amounts, no obvious dysphagia. Frail.
- Wants to go home to daughter's home. Daughter works full time and no POC in place as yet.
- Discussions about possible PEG insertion amongst inpatient team.

Scenario 3

Mr J. 72 year old man

- Diagnosed with limb onset MND in Jan 22. Lives with his wife.
- Weight is stable with no eating or drinking difficulties. He has a history of Type 2 Diabetes for which he takes Metformin.
- Mr J will not engage with any Advance Care Planning and only will only consider any interventions if they have immediate perceived practical benefit.
- Agreed to dietetic referral in Sep 2022 following some weight loss. Would not engage in conversations re gastrostomy. Given supplements.
- Oct 23: concerns about respiratory failure and continued weight loss. Poor appetite and getting weaker.

Feeding dilemmas

Overall question:

How would you approach this situation within the MDT?

- Facilitator may give specific prompts for your scenario.
- Discuss in your groups for 15 minutes.
- Move on to next scenario- e.g. if you start on no. 2, move to no. 3
- Feedback to whole group

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Final thoughts

Complete evaluations

Complete photo consent forms

Hand in badges

Sign up to our mailing list:
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thank you for coming!

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