

PALLIATIVE CARE AND NEUROLOGY WHAT DO WE HAVE TO LEARN FROM EACH OTHER?

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OUTLINE OF PRESENTATION

- **WHY DO WE NEED TO LEARN FROM EACH OTHER?**
- **WHAT CAN WE LEARN FROM EACH OTHER?**
- **THE HUNTINGTON'S DISEASE EXAMPLE**

WHY DO WE NEED TO LEARN FROM EACH OTHER? (1)

“IN ITS BROADEST SENSE, PALLIATIVE CARE IS AN APPROACH RATHER THAN A DISCRETE INTERVENTION. CARING, THE PALLIATIVE WAY, IS TO FOCUS ON THE MEDICAL, NURSING, SPIRITUAL, EMOTIONAL AND SOCIAL NEEDS OF PATIENTS AND THEIR FAMILIES..... IT IS THUS A STYLE OF CARING: AN ACKNOWLEDGEMENT OF THE NEED TO APPROACH PATIENTS ‘HOLISTICALLY’ AND TO BE INVENTIVE IN THE RANGE OF SOLUTIONS OFFERED”

(ROBBINS 1997)

WHY DO WE NEED TO LEARN FROM EACH OTHER? (2)

“MANY PALLIATIVE CARE SPECIALISTS IN THE UK..... HAVE BACKGROUNDS IN ONCOLOGY. THEY DO NOT HAVE, AND CANNOT BE EXPECTED TO HAVE, AN IN-DEPTH UNDERSTANDING OF ALL THE DISEASES..... THE MAJORITY OF NON-CANCER PATIENTS WITH PALLIATIVE CARE NEEDS WILL CONTINUE TO HAVE THEIR NEEDS MET WITHIN THEIR CURRENT HEALTH CARE SETTING. EFFECTIVE PARTNERSHIPS ARE THEREFORE REQUIRED..... NO ONE DISCIPLINE OR SPECIALTY WILL HAVE THE ANSWERS. EDUCATION, WHETHER FORMAL OR INFORMAL, WILL NEED TO BE TWO-WAY, AS WILL ACCESS TO CONSULTANCY SERVICES AND ADVICE”

(ADDINGTON-HALL & HIGGINSON 2001)

WHY DO WE NEED TO LEARN FROM EACH OTHER? (3)

- **TO MEET THE NEEDS OF PATIENTS AND THEIR FAMILIES/CAREGIVERS IN A TIMELY AND APPROPRIATE MANNER USING THE RESOURCES THAT ARE AVAILABLE**

WHY DO WE NEED TO LEARN FROM EACH OTHER? (4)

- **TO MEET THE REQUIRMENTS OF LOCAL AND NATIONAL POLICY e.g.**
 - **NHS END OF LIFE CARE PROGRAMME – THE KEY OBJECTIVE OF THIS IS ‘TO OFFER ALL ADULT PATIENTS NEARING THE END OF LIFE, REGARDLESS OF THEIR DIAGNOSIS, THE CHOICE AND ACCESS TO HIGH QUALITY END OF LIFE CARE’**
 - **NSF FOR LONG-TERM NEUROLOGICAL CONDITIONS – ONE OF THE QUALITY REQUIREMENTS IS THAT SERVICES MUST BE PERSON-CENTRED AND A FURTHER REQUIREMENT IS THAT PEOPLE IN THE ADVANCED STAGES OF LONG-TERM NEUROLOGICAL CONDITIONS ARE PROVIDED WITH HIGH QUALITY PALLIATIVE CARE SERVICES**

WHY DO WE NEED TO LEARN FROM EACH OTHER? (5)

- **THE NSF GOES ON TO SAY THAT
“PROFESSIONALS WORKING IN NEUROLOGY,
REHABILITATION AND PALLIATIVE CARE NEED TO
WORK CLOSELY TOGETHER AND WITH PRIMARY
CARE STAFF.....COMBINING THEIR EXPERTISE TO
SUPPORT PEOPLE IN THE ADVANCED STAGES OF
LONG-TERM NEUROLOGICAL CONDITIONS”**

WHY DO WE NEED TO LEARN FROM EACH OTHER? (6)

- **SOME WAYS IN WHICH THE NSF SUGGESTS THIS COULD BE ACHIEVED INCLUDE:**
 - **SPECIALIST PALLIATIVE CARE TEAMS WORKING ALONGSIDE SPECIALIST NEUROLOGY AND NEURO-REHABILITATION TEAMS IN ORDER TO PROMOTE CONSISTENT, SHARED PRACTICE**
 - **PALLIATIVE CARE SKILLS TRAINING BEING GIVEN TO NEUROLOGISTS AND NEUROLOGY SPECIALIST NURSES ETC**
 - **TRAINING IN RELEVANT ASPECTS OF NEUROLOGY AND NEURO-REHABILITATION FOR SPECIALIST PALLIATIVE CARE TEAMS**

WHY DO WE NEED TO LEARN FROM EACH OTHER? (7)

- **RESOURCES ARE LIMITED – FUNDING, STAFF ETC**
- **NEED TO PREVENT DUPLICATION AND FRAGMENTATION OF CARE/SERVICES**

WHAT CAN WE LEARN FROM EACH OTHER? (1)

- **NEUROLOGY CAN LEARN FROM THE 'PALLIATIVE CARE APPROACH' (ADDINGTON-HALL AND HIGGINSON 2001)**
 - **A FOCUS ON QUALITY OF LIFE, INCLUDING GOOD SYMPTOM MANAGEMENT**
 - **A HOLISTIC, PERSON CENTERED APPROACH, TAKING INTO CONSIDERATION AN INDIVIDUAL'S PAST AND PRESENT EXPERIENCES**
 - **CARE AND SUPPORT FOR THE PERSON'S LOVED ONES/CAREGIVERS**
 - **CHOICE**
 - **OPEN AND SENSITIVE COMMUNICATION**

WHAT CAN WE LEARN FROM EACH OTHER? (2)

- **PALLIATIVE CARE CAN LEARN FROM NEUROLOGY TOO.**
- **WHILST MANY OF THE SYMPTOMS AND ISSUES THAT ARISE IN THE ADVANCED STAGES OF NEUROLOGICAL CONDITIONS ARE SIMILAR TO THOSE IN CONDITIONS SUCH AS CANCER, SOME PROBLEMS ARE MORE SPECIFIC TO NEUROLOGICAL DISEASES**

WHAT CAN WE LEARN FROM EACH OTHER? (3)

- **COGNITIVE DIFFICULTIES/DEMENTIA**
- **BEHAVIOURAL DIFFICULTIES**
- **COMMUNICATION PROBLEMS**
- **MENTAL CAPACITY**
- **SYMPTOMS RELATED TO NEUROLOGICAL DISEASE PATHWAY e.g. INVOLUNTARY MOVEMENTS, NEUROPATHIC PAIN, SPASTICITY**
- **SLOW DISEASE PROGRESSION**

THE HUNTINGTON'S DISEASE EXAMPLE (1)

- **HUNTINGTON'S DISEASE IS A COMPLEX NEURODEGENERATIVE CONDITION**
- **INHERITED IN AN AUTOSOMAL DOMINANT WAY THEREFORE ANY CHILDREN OF AN AFFECTED PERSON ARE AT 50% RISK OF THE CONDITION**
- **MEAN AGE OF SYMPTOM ONSET IS 33 – 44 YEARS**
- **THE DISEASE PROGRESSES OVER A PERIOD OF APPROXIMATELY 15-20 YEARS.**
- **CURRENTLY NO PREVENTATIVE OR CURATIVE TREATMENT AVAILABLE**
- **MOST COMMON CAUSE OF DEATH IS PNEUMONIA**

THE HUNTINGTON'S DISEASE EXAMPLE (2)

- **CHARACTERISED BY A TRIAD OF SYMPTOMS AND SIGNS**
- **MOTOR SYMPTOMS:**
 - **INVOLUNTARY – CHOREA, DYSTONIA, BRADYKINESIA AND RIGIDITY**
 - **VOLUNTARY – EYE MOVEMENTS, GAIT, SPEECH, SWALLOW, BALANCE AND CO-ORDINATION**

THE HUNTINGTON'S DISEASE EXAMPLE

(3)

- **PSYCHIATRIC SYMPTOMS – STUDIES HAVE SHOWN THAT UP TO 75% OF PEOPLE WITH HD SUFFER WITH PSYCHIATRIC PROBLEMS AT SOME STAGE IN THEIR ILLNESS**
- **DEPRESSION, ANXIETY, IRRITABILITY AND AGGRESSION, OBSESSIVE COMPULSIVE DISORDER, MANIA, HALLUCINATIONS, DISORDERS OF SEXUAL FUNCTION, DRUG/ALCOHOL ABUSE, PSYCHOSIS (RARE)**

THE HUNTINGTON'S DISEASE EXAMPLE

(4)

- **COGNITIVE IMPAIRMENT – THE COGNITIVE SYMPTOMS VARY GREATLY AND INCREASE OVER TIME.**
- **EXECUTIVE FUNCTIONS ARE IMPAIRED**
 - **ABILITY TO PLAN AND ORGANISE**
 - **MONITOR OWN BEHAVIOUR**
 - **THINK AND BE FLEXIBLE.**
 - **MULTI-TASK AND SWITCH FROM ONE TASK TO ANOTHER**
- **PEOPLE ALSO EXPERIENCE IMPAIRED MEMORY, CONCENTRATION, VERBAL FLUENCY**
- **CONSEQUENTLY TASKS, EVEN ROUTINE ONES, MAY TAKE MUCH LONGER**

THE HUNTINGTON'S DISEASE EXAMPLE (5)

- **LOSS OF IMPULSE CONTROL**
- **PERSEVERATIVE BEHAVIOUR**
- **LACK OF INSIGHT**
- **ABILITY TO GIVE INFORMED CONSENT AND MAKE INFORMED CHOICES DIMINSHES**

THE HUNTINGTON'S DISEASE EXAMPLE

(6)

- **OTHER ISSUES INCLUDE:**
 - **WEIGHT LOSS – MANY PEOPLE WITH HUNTINGTON'S DISEASE LOSE WEIGHT, THE EXACT CAUSE OF WHICH IS UNKNOWN. WEIGHT LOSS IS ASSOCIATED WITH MORE RAPID DISEASE PROGRESSION. FOR SOME A DIET OF 4000-6000 CALORIES IS REQUIRED IN ORDER TO MAINTAIN WEIGHT**
 - **SLEEP – A NUMBER OF PATIENTS WITH HD EXPERIENCE SLEEP PROBLEMS WHICH CAN INCLUDE EXCESSIVE DAYTIME SLEEPINESS, INSOMNIA AND REVERSAL OF SLEEP-WAKE CYCLE**

THE HUNTINGTON'S DISEASE EXAMPLE (7)

- **THE HEREDITARY ASPECT OF THE DISEASE CAUSES A NUMBER OF ETHICAL AND EMOTIONAL ISSUES FOR INDIVIDUALS AND THEIR FAMILIES.**
- **CHILDREN OF AN AFFECTED PERSON MAY BE WITNESSING THEIR PARENT'S DISEASE PROGRESSION WHILST DEALING WITH THEIR OWN STATUS – PERHAPS EARLY SYMPTOMATIC, GENE POSITIVE, AT RISK, GENE NEGATIVE**
- **PARTNERS OF AN AFFECTED PERSON CARING FOR THAT PERSON AND LIVING WITH FEARS FOR CHILDREN/GRANDCHILDREN**

THE HUNTINGTON'S DISEASE EXAMPLE

(8)

- **AFFECTED INDIVIDUALS WITHIN THE SAME FAMILY MAY BE AT DIFFERENT STAGES OF THE DISEASE**
- **AN AFFECTED PERSON NOT ONLY HAS TO DEAL WITH THEIR OWN ADVANCING DISEASE BUT THEIR FEELINGS ABOUT RISKS TO ANY CHILDREN/GRANDCHILDREN THEY MAY HAVE**
- **GUILT**
- **HIDING DIAGNOSIS AND ITS IMPLICATIONS**

THE HUNTINGTON'S DISEASE EXAMPLE (9)

- MAJORITY OF INDIVIDUALS WITH LATE-STAGE HUNTINGTON'S DISEASE LIVE IN RESIDENTIAL CARE. THESE INCLUDE SPECIALIST NEUROLOGICAL UNITS SUCH AS SUE RYDER CENTRES AND THE ROYAL HOSPITAL FOR NEURODISABILITY IN PUTNEY; SPECIALIST HD UNITS WITHIN NURSING HOMES AND GENERAL NURSING HOMES.
- SOME PATIENTS ARE ABLE TO REMAIN AT HOME WITH APPROPRIATE CARE PACKAGES – THIS WILL NOT ONLY DEPEND ON THE AVAILABLE REOURCES BUT ALSO ON THE PARTICULAR SYMPTOMS THAT A PERSON HAS

THE HUNTINGTON'S DISEASE EXAMPLE (10)

- **PEOPLE WITH HUNTINGTON'S DISEASE REQUIRE DIFFERENT TYPES OF CARE AND SUPPORT THROUGH THE DIFFERENT STAGES OF THEIR CONDITION, DEPENDING ON THEIR PARTICULAR SYMPTOMS AND NEEDS AND THE NEEDS OF THEIR FAMILIES/CAREGIVERS**
- **HUNTINGTON'S DISEASE IS AN EXAMPLE OF A VERY COMPLEX NEUROLOGICAL CONDITION WITH SPECIALIST NEEDS FOR PALLIATIVE CARE.**
- **A MULTIDISCIPLINARY APPROACH IS VITAL.**

THE HUNTINGTON'S DISEASE EXAMPLE

(11)

- **MANY SYMPTOMS/PROBLEMS THAT ARISE IN ADVANCED HUNTINGTON'S DISEASE ARE COMMON IN PALLIATIVE CARE**
e.g.
 - **PAIN**
 - **AGITATION AND RESTLESSNESS**
 - **DYSPHAGIA AND ASSOCIATED PROBLEMS – CHOKING, WEIGHT LOSS, MALNOURISHMENT, ASPIRATION PNEUMONIA**
 - **SALIVARY DRIBBLING**
 - **SLEEP PROBLEMS**
 - **MEDICAL COMPLICATIONS SUCH AS INFECTIONS, BREAKDOWN OF SKIN**
 - **FAMILY/CAREGIVER SUPPORT**
 - **BEREAVEMENT AND LOSS**

THE HUNTINGTON'S DISEASE EXAMPLE (12)

- **CASE EXAMPLE ONE:**

- 39 YEAR OLD LADY WITH ADVANCED HD, DIAGNOSED WITH HUNTINGTON'S DISEASE AT AGE 30 YEARS
- LIVING AT HOME WITH HUSBAND (NO CHILDREN) AND CARE PACKAGE, WHICH WAS RECENTLY INCREASED TO 24 HOUR CARE.
- FEW COGNITIVE PROBLEMS, DEPRESSION WELL CONTROLLED BUT INVOLUNTARY MOVEMENTS NAMELY BALLISTIC CHOREA EXTREMELY PROBLEMATIC.
- A NUMBER OF INCIDENTS OCCURRED WHERE CARERS WERE HIT AND THE CARE AGENCY FELT THAT IT WAS NO LONGER SAFE FOR THEIR CARERS TO LOOK AFTER HER.

THE HUNTINGTON'S DISEASE EXAMPLE (13)

- **SHE HAD A PREVIOUS ADMISSION TO NHNN FOR MANAGEMENT OF SYMPTOMS WHICH WAS EFFECTIVE FOR A SHORT TIME. HOWEVER THE ADMISSION WAS VERY STRESSFUL FOR BOTH THE PATIENT AND HER HUSBAND – THEY LIVE OVER 200 MILES FROM THE HOSPITAL**
- **ALSO UNDER THE CARE OF A LOCAL NEUROLOGIST**

THE HUNTINGTON'S DISEASE EXAMPLE (14)

- **SHE WAS ADMITTED TO LOCAL HOSPICE FOR SYMPTOM MANAGEMENT**
- **THIS ALLOWED US TO LIAISE WITH THE PALLIATIVE CARE TEAM AROUND MEDICATIONS FOR HER MOVEMENTS**
- **ALTERATIONS TO MEDICATIONS WERE DONE IN THE SAFE AND SUPPORTIVE ENVIRONMENT OF THE HOSPICE**
- **GOOD COMMUNICATION AND SHARING OF THOUGHTS, IDEAS AND CONCERNS WAS KEY**
- **MULTIDISCIPLINARY APPROACH TO PLANNING INVOLVING THE PATIENT AND HER HUSBAND, THE PALLIATIVE CARE TEAM, LOCAL NEUROLOGIST, PRIMARY CARE SERVICES, SOCIAL SERVICES WITH INPUT FROM NHNN VIA TELEPHONE AND EMAIL**

THE HUNTINGTON'S DISEASE EXAMPLE (15)

- TITRATION OF MEDICATIONS, PLANNING OF CARE AND PSYCHOSOCIAL SUPPORT PROVIDED BY THE MULTIDISCIPLINARY TEAM HAS MEANT THAT SHE IS NOW AT HOME, WHERE BOTH SHE AND HER HUSBAND WANT HER TO BE

SUMMARY (1)

- **NEUROLOGY CAN DEVELOP AN UNDERSTANDING OF THE PRINCIPLES OF PALLIATIVE CARE AND INCORPORATE THESE INTO PRACTICE.....**
- **PALLIATIVE CARE CAN DEVELOP AN UNDERSTANDING OF THE NEUROLOGICAL DISEASES AND THEIR TREATMENTS.....**
- **AND TOGETHER THEY CAN WORK TOWARDS THE BETTER MANAGEMENT OF SYMPTOMS (PHYSICAL AND PSYCHOSOCIAL) FOR PEOPLE WITH NEUROLOGICAL CONDITIONS AND THEIR LOVED ONES/CAREGIVERS**

SUMMARY (2)

“....MANY OF THE SYMPTOMS TO BE TREATED AND MUCH OF THE GENERAL MANAGEMENT WILL BE RELEVANT TO OTHER SITUATIONS....TERMINAL CARE SHOULD NOT ONLY BE PART OF ONCOLOGY BUT OF GERIATRIC MEDICINE, NEUROLOGY, GENERAL PRACTICE AND THROUGHOUT MEDICINE”

(SAUNDERS & BAINES 1983)

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