

## **Health and functional status of long term adult medulloblastoma/pnet survivors: A report from the childhood cancer survivor study.**

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**Background:** Medulloblastoma is the most common malignant childhood CNS tumor. Survival rates increased from 40% to 70% during the past 30 years. The long-term risks of chronic medical conditions, adverse health status, and reduced psychosocial functioning in aging survivors of childhood medulloblastoma/PNET are not known.

**Methods:** Using the Childhood Cancer Survivor Study cohort, we analyzed the long-term outcomes of 380 5+ year survivors of medulloblastoma/PNET (median age at last follow-up: 30 years, range 7-53), diagnosed between 1970-1986. A sibling cohort (n=4031) served as a comparison population. Neurological outcomes and cataracts were analyzed as time-to-event data with cumulative incidence, with Cox regression models used to calculate hazard ratios (HR) and 95% confidence intervals (CI). Memory complications, educational status, marital status, independent living, employment status, income, and fertility were assessed cross-sectionally using generalized linear models. Comparisons were adjusted for age and sex. **Results:** By 30 years post diagnosis, mortality was 29% (CI 23-36). Cumulative incidence of second malignant neoplasm was 8% (CI 5-12), and recurrence of the original cancer 18% (CI 14-22) at 30 years. Cumulative incidence for hearing loss was 37% (CI 31-44), seizures 34% (CI 29-39), balance problems 72% (CI 67-77), tinnitus 30% (CI 23-37) and cataracts 14% (CI 9-18). Relative to siblings, survivors reported a higher risk of hearing loss (HR=36.0, CI 23.6-54.9), seizures (HR=12.8, CI 9.0-18.1), poor balance (HR=10.4, CI 6.7-15.9), tinnitus (HR=4.8, CI 3.5-6.8), and cataracts (HR=31.8, CI 16.7–60.5). Survivors were less likely to earn a bachelor's degree (RR=0.49, CI 0.39-0.60), to marry (RR=0.35, CI 0.29–0.42), to live independently (RR=0.58, CI 0.52-0.66) and to have a pregnancy or a partner become pregnant (RR=0.23, CI 0.17–0.3). **Conclusions:** Among adult survivors of childhood medulloblastoma/PNET, significant neurologic morbidity and lower levels of educational attainment and social independence exist. Given the high survival rates for these children, interventions to reduce these sequelae and support the survivors should be a high priority.